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People living with Parkinson's disease and their caregivers:  
A systematic review of psychosocial interventions  
and

Psychological adjustment in people living with Parkinson's disease  
and their caregivers: the role of coping, illness beliefs and self-  
compassion



THE UNIVERSITY  
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Doctorate in Clinical Psychology

University of Edinburgh

June 2019

## **DClinPsychol Declaration of Own Work**

**Name:** Lorna Hodge

**Title of Work:** People living with Parkinson's disease and their caregivers: A systematic review of psychosocial interventions and Psychological adjustment in people living with Parkinson's disease and their caregivers: the role of coping, illness beliefs and self-compassion.

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## **Lay summary**

Parkinson's disease (PD) is a condition which progressively damages parts of the brain, leading to difficulties with physical movement, alongside additional physical and mental symptoms. PD can impact on the wellbeing of both the people experiencing the condition and their caregivers. Therefore, this thesis firstly aimed to address whether psychosocial interventions for people living with PD and caregivers may have psychological and any additional benefits. A review was undertaken of studies which delivered psychosocial interventions to both people living with PD and caregivers. This review found that psychosocial interventions, which include both people living with PD and caregivers, may provide psychological benefits for people living with PD. There was very limited evidence to suggest benefits for caregivers participating in these psychosocial interventions. This review highlights that research into psychosocial interventions for people living with PD and their caregivers has grown over the last decade. Nevertheless, more research of a greater quality is required to draw conclusions of the benefits from psychosocial interventions delivered to people living with PD alongside caregivers.

This thesis secondly aimed to explore what may contribute to people living with PD and caregivers adjusting better to living with the disease. Therefore, a postal survey was undertaken by people living with PD and their caregivers. It was found that beliefs participants living with PD have towards their illness, the number of coping responses they engage with, and how compassionate they are to themselves, are all associated with how successful their adjustment is living with PD. Due to the small sample size, it was not possible to establish what factors may predict how well caregivers adjust to supporting people living with PD. However, the findings do indicate it would be beneficial to undertake further research of a larger and more representative sample to establish the role of illness beliefs, coping responses and self-compassion in psychological adjustment in people with PD and their caregivers.

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## **Thesis Abstract**

This thesis comprises of a systematic review and an empirical study aimed to gain a greater understanding of the psychological needs of both people living with Parkinson's disease (PD), their caregivers, and how these needs can be met. The systematic review aimed to evaluate the effectiveness of psychosocial interventions, where people living with PD and their caregivers are involved in the intervention (dyad-based), on psychological and additional outcomes measured. The review included 13 studies which met predefined eligibility criteria. Due to varied methodological quality of the studies, this review to an extent suggests that dyad-based psychosocial interventions may provide psychological benefits for people living with PD. Whereas, there was no substantive evidence to suggest dyad-based psychosocial interventions are effective for caregivers. More high-quality research is required to conclusively establish the effectiveness of these interventions for both people living with PD and their caregivers. The empirical study extended previous research examining the relationship between illness beliefs and coping with psychological adjustment (in terms of anxiety, depression and quality of life) in people living with PD and caregivers, whilst developing research in to the role of self-compassion within this process. A cross-sectional survey design with participants living with PD (N=66) and their caregivers (N=24) with the following measures was utilised; Brief COPE, Brief-Illness Perception Questionnaire, Self-Compassion Scale, Hospital Anxiety and Depression Scale, Parkinson's disease Questionnaire 8-item and Adult Carer Quality of Life Questionnaire. The results of the study provided further evidence for the relationship between illness beliefs and psychological adjustment outcomes in people living with PD. In addition, the study provided preliminary evidence of a relationship between self-compassion and psychological adjustment outcomes of psychological distress in people living with PD. Further research of a larger and more representative sample is required to establish the role of illness beliefs, coping responses and self-compassion in psychological adjustment in both people living with PD and their caregivers.

## **Chapter 1: Systematic Review<sup>1</sup>**

### **A systematic review of psychosocial interventions for people living with Parkinson's disease and their caregivers**

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<sup>1</sup> This review has been written in accordance with submission guidelines for the journal *Clinical Rehabilitation*, however, margins and tables have followed the guidance for thesis submission. A copy of the guidelines can be found in Appendix 1.

## **Abstract**

**Objectives:** This systematic review aimed to evaluate the effectiveness of psychosocial interventions, where people living with Parkinson's disease (PD) and caregivers are involved in the intervention (dyad-based), on psychological and additional outcomes measured for people living with PD and caregivers.

**Data sources:** The following were systematically searched from database inception to October 2018; MEDLINE, PsycINFO, PsycARTICLES, ProQuest, Scopus, Teacher Reference Centre, Education Source, Cochrane Central Register of Controlled Trials, ERIC, EMBASE, ASSIA.

**Review methods:** A protocol was registered with PROSPERO (CRD42018112992). All study designs of dyad-based psychosocial interventions were reviewed where psychological outcomes were reported for participants living with PD and caregivers. The Effective Public Health Practice Project Quality Assessment Tool and customised quality criteria were applied to assess methodological quality of included studies, with a proportion (70%) assessed for inter-rater reliability.

**Results:** Thirteen studies were included in the review. Studies were predominantly Cognitive Behavioural Therapy (CBT) or CBT-informed interventions, with heterogeneity in design, delivery type, caregiver involvement, methodological quality, and outcomes reported. The majority of studies demonstrated statistically significant improvements in psychological outcomes of people living with PD. Interventions targeting depressive disorders in people living with PD were effective at reducing depression symptoms, and CBT was effective at reducing symptoms of anxiety. There was no substantive evidence to suggest dyad-based psychosocial interventions are effective for caregivers.

**Conclusion:** Research of varied methodological quality suggest a role for psychosocial interventions for people living with PD, however, more high-quality research is required to conclusively establish the effectiveness of these interventions for both people living with PD and their caregivers.

**Key words:** Parkinson's disease, caregivers, psychosocial interventions, systematic review, dyad-based interventions

## **Introduction**

Parkinson's disease (PD) is the second most common neurodegenerative disorder primarily affecting people in the later years of their life.<sup>1</sup> PD is predominantly caused by the death of dopamine producing cells within the brain.<sup>2</sup> Dopamine has several functions as a neurotransmitter including regulating movement within the body. With the reduction in the production of dopamine, people living with PD develop several primary symptoms including slow movement, tremors and stiffness.<sup>2</sup> PD motor symptoms can also be accompanied by nonmotor symptoms such as difficulties with sleep, mood, apathy, fatigue and cognition.<sup>3</sup> As the disease progresses motor and nonmotor symptoms may worsen, resulting in a loss of independence.<sup>4</sup> There is no known cure for PD, with current treatments primarily focused on reducing motor symptoms. However, the psychological impact of PD can be overlooked.<sup>5</sup> Both primary symptoms of PD and the adjustment to living with a long-term health condition can affect the psychological wellbeing of people living with PD.<sup>6</sup>

PD does not only impact on the people living with the condition, those supporting them may also experience psychological distress. Caregiver's quality of life and psychological wellbeing can be negatively impacted by supporting those living with PD, and both motor and nonmotor symptoms associated with caregiver burden.<sup>7,8</sup> As the disease progresses family members and partners commonly take on the role of caregivers.<sup>9</sup> The needs of these caregivers are often overlooked.<sup>10</sup> Therefore,

interventions which consider the needs of both people living with PD and their caregivers are warranted.

The prevalence of PD within the UK is predicted to increase by 56% by 2045,<sup>11</sup> as a result there is a growing need to better understand how to support people living with PD and their caregivers. Especially considering that as the population is continuing to age, there is likely to be a greater number of older adults with long-term conditions such as PD with their family providing informal care. The potential impact this has on the current health and social services has not gone unnoticed. The recent integration of health and social care within Scotland was driven by the need to improve preventative and anticipatory care for service users, caregivers and families.<sup>12</sup> Psychosocial interventions may be an approach that could help meet the needs of this population.

Researchers have explored the effectiveness of psychosocial interventions for people living with PD.<sup>5,13,14</sup> Previous reviews have highlighted the limited research, however, studies that have been undertaken do indicate that psychosocial interventions may be effective in improving anxiety and depression.<sup>5,13</sup> Yet the methodological quality of included studies may undermine reported benefits.<sup>13</sup> Research has demonstrated that psychological outcomes such as quality of life and stress may also be impacted when living with PD.<sup>15</sup> It would be beneficial to explore the effect of psychosocial interventions on additional outcomes.

A clinical review by Koychev & Okai<sup>14</sup> explored the evidence for CBT in managing nonmotor symptoms of PD, specifically depression, anxiety, impulse-control disorders and insomnia. Authors found growing research for the use of CBT for managing nonmotor symptoms of PD, whilst also reviewing research of CBT interventions for caregivers of people with PD.<sup>14</sup> However, there is a growing evidence-base for third wave therapies, such as compassion focused therapy (CFT) and acceptance and commitment therapy (ACT), in the management of neurodegenerative conditions for patients and caregivers.<sup>16,17</sup> These have yet to be taken into consideration when assessing the effectiveness of psychosocial interventions for those impacted by PD.

As previously discussed, it is also important to consider the psychological implications for those supporting people living with PD. Despite a growing evidence-base for psychosocial interventions for people living with PD, there has been limited research exploring the effectiveness of psychosocial interventions with caregivers of people living with PD.<sup>10</sup> In 2008, Hempel et al.<sup>10</sup> conducted a systematic scoping review of psychosocial interventions for caregivers of people living with PD. They found that caregivers were typically assigned the role of adjunctive therapist.<sup>10</sup> Therefore, their own psychological needs were not necessarily the aim of the intervention. Research has demonstrated that the quality of life of people living with PD may be correlated with the emotional wellbeing of their caregiver.<sup>18</sup> As a result, interventions that are delivered to people living with PD alongside their caregivers may be beneficial for both, should the psychological outcomes of these dyads have direct impact on each other's outcomes.

Research within other long-term health conditions has demonstrated the benefits of dyad-based psychosocial interventions,<sup>19,20</sup> with growing research within PD considering the needs of both people living with PD and their caregivers.<sup>21</sup> Yet to-date no systematic review has focused on the effectiveness of dyad-based psychosocial interventions for people living with PD.

### ***Objective***

This systematic review aimed to evaluate the effectiveness of psychosocial interventions where both people living with PD and their caregivers are involved in the intervention, and psychological outcomes are evaluated for both caregiver and the person living with PD. The research questions are as follow:

- What are the effects of dyad-based psychosocial interventions on psychological outcomes of both people living with PD and their caregivers?
- What are the effects of dyad-based psychosocial interventions on people living with PD and their caregivers on any additional outcomes measured?

### **Methods**

#### ***Protocol***

A protocol was registered with PROSPERO registration number: 2018 CRD42018112992 ([http://www.crd.york.ac.uk/PROSPERO/display\\_record.php?ID=CRD42018112992](http://www.crd.york.ac.uk/PROSPERO/display_record.php?ID=CRD42018112992)).

### *Eligibility Criteria*

The following outlines the selection criteria for relevant articles, based on the PICOS guidelines;<sup>22</sup>

#### *Population(s)*

This review included all people aged over 18 years. The participants included were people with a clinical diagnosis of PD and caregivers of people with a clinical diagnosis of PD. People with a diagnosis of secondary parkinsonism, Parkinson-plus or other neurodegenerative diseases were not included within this review.

#### *Intervention(s)*

Studies that evaluated the effectiveness of any psychosocial intervention which measured psychological outcomes of both people living with PD and caregivers of people with living PD were included. Psychosocial interventions which delivered their intervention to people living with PD and their caregivers were included. All formats of delivery of the psychosocial intervention were included e.g. individual, group, telephone etc. The psychosocial intervention was required to have focused primarily on psychological and/or social factors. In order to evaluate whether reported outcomes were the result of the psychosocial intervention, studies were excluded when the intervention included the addition of further therapies (i.e. exercise, occupational therapy, speech and language therapy) unless it was reported as usual care.



### *Comparison(s)*

The review included studies with and without comparator groups. Studies with comparator groups were included, regardless of the type of comparators e.g. intervention control, waitlist control and treatment as usual.

### *Outcome measure(s)*

Studies were included where psychological outcomes for both people living with PD and caregivers of people living with PD were taken at baseline and post intervention. Psychological outcomes reported by studies were varied e.g. anxiety, depression, quality of life, caregiver burden and caregiver distress.

### *Study design(s)*

The review considered quantitative, qualitative and mixed-method study designs reported prior to November 2018. The review considered multiple study designs with no date limit set for the search, as previous research outlined limited literature within this area.<sup>5,10</sup> The review included randomised controlled trials (RCTs), quasi-experimental designs and case series. Published and grey literature were considered, with authors of grey literature being followed up for further information as required. Studies reported in English and studies reported in Spanish with an English abstract were included due to limited means to translate non-English language studies.

### *Literature Search Strategy*

A search strategy was designed with consultation from a librarian experienced in systematic reviews. No publication period restrictions were set. Each database was

searched from their inception date, however, research/trials published after October 2018 were not included. The search was completed on the 3<sup>rd</sup> November 2018 using the following search terms: ((Parkinson\*) AND (“psychosocial” or "psycho\* intervention" or "cognitive behavio\*" or “cbt” or "cognitive therap\*" or “psychoeducation\*” or "compassion focus\* therap\*" or "acceptance and commitment therap\*" or "family therap\*" or "mindfulness therap\*" or "mindfulness\* intervention\*"))).

The following electronic databases were used; MEDLINE, PsycINFO, PsycARTICLES, ProQuest, Scopus, Teacher Reference Centre, Education Source, Cochrane Central Register of Controlled Trials (CENTRAL) (Cochrane Library), ERIC, EMBASE, ASSIA. In addition to the database search, references of included studies were reviewed, and searches on Google Scholar and PROSPERO were undertaken. No further records were identified by these means.

### ***Data Collection and Analysis***

#### ***Selection of Studies***

The studies resulting from the outlined search strategy were initially screened by their title and abstract against the PICOS criteria. Full articles were then further screened against the PICOS criteria. The first author completed the screening from the search to the included articles. Where articles could not be established by the first author either due to being written in Spanish or unclear whether they met the criteria (n=2,

n=3 respectively), they were discussed with the third author and rated against the PICOS guidelines.

### *Data Extraction*

The first author compiled the data from all included articles using a data extraction form designed for this review. The data extraction form was developed using guidance from the Centre for Reviews and Dissemination (CRD).<sup>23</sup> Therefore, the data extraction form included the following; author, year of publication (recording whether published as a full-text or abstract only), study design, location of study, when the study was recorded, sample size of participants (including attrition), participant characteristics, intervention, nature of the control condition, treatment duration, follow-up period, analyses, number of participants included in the analyses, study outcomes (including primary and secondary outcomes), study sponsorship and main results (including effect sizes). Due to previous research demonstrating a heterogeneity of the delivery of interventions to both people with PD and caregivers within this area,<sup>5,10</sup> in-depth details regarding the type, delivery, caregiver involvement and duration of the interventions were collected.

### *Quality Assessment*

The Effective Public Health Practice Project Quality Assessment Tool (EPHPP) was used for quality appraisal,<sup>24</sup> with two additional criteria designed for this study. The additional criteria were developed in line with the CRD recommendations. The EPHPP quality assessment tool provides a global rating,<sup>25</sup> which is derived from the ratings of the following components; selection bias, study design, confounders, blinding, data

collection methods, and withdrawals and dropouts. However, the additional ratings have been provided for the EPHPP components of analysis and intervention integrity, alongside the ratings for quality of reporting and generalisability designed specifically for this study. These four additional quality rated components may not contribute to the risk of bias, yet they are indicators of the methodological quality of the included studies. All criteria items were classified in terms of 'strong', 'moderate', 'weak' or 'not applicable'. The first author independently assessed all included articles, and the second author assessed 70% (n=9) of included articles using the quality assessment criteria. Kappa co-efficient for overall agreement of 0.76 was found, indicating adequate inter-rater agreement. Where there were discrepancies, these were discussed and amended if there was agreement. Agreement was found on all discrepancies, with the cause of discrepancies being primarily due to interpretation of the criteria. The first author applied the agreed interpretation of the criteria to the additional studies (n=4) independently reviewed.

## **Results**

### ***Study Selection***

The electronic search identified 2142 unique results following removal of duplications. 1925 search results were excluded at the stage of title and abstract screening. The main cause for exclusion at this stage was incorrect population and non-intervention studies. Following full review, a further 207 results were excluded. Authors of abstracts were also contacted to ascertain whether a full article was available (n=10). At full articles review, unsuitable intervention (n=103) and unsuitable outcomes (n=35) were the main causes for exclusion at this stage. Where studies included caregiver outcomes

with information lacking regarding caregiver involvement, further information was sought from authors (n=3). In cases where data from the same sample were reported in duplicate articles, the most recent article was included (see Appendix 2). A final 13 studies were included for qualitative synthesis. Figure 1 provides an overview of studies considered at each stage.

### ***Characteristics of Included Studies***

Thirteen studies were included for qualitative synthesis, summarised in Table 1. All studies had been published in peer-reviewed journals,<sup>26-37</sup> except for one study which was an unpublished thesis project.<sup>38</sup> Studies were conducted between 2003 and 2018. Five studies were carried out in Europe,<sup>26-28,35,37</sup> seven carried out in North America,<sup>29,30,32-34,36,38</sup> and one carried out in Australia.<sup>31</sup>

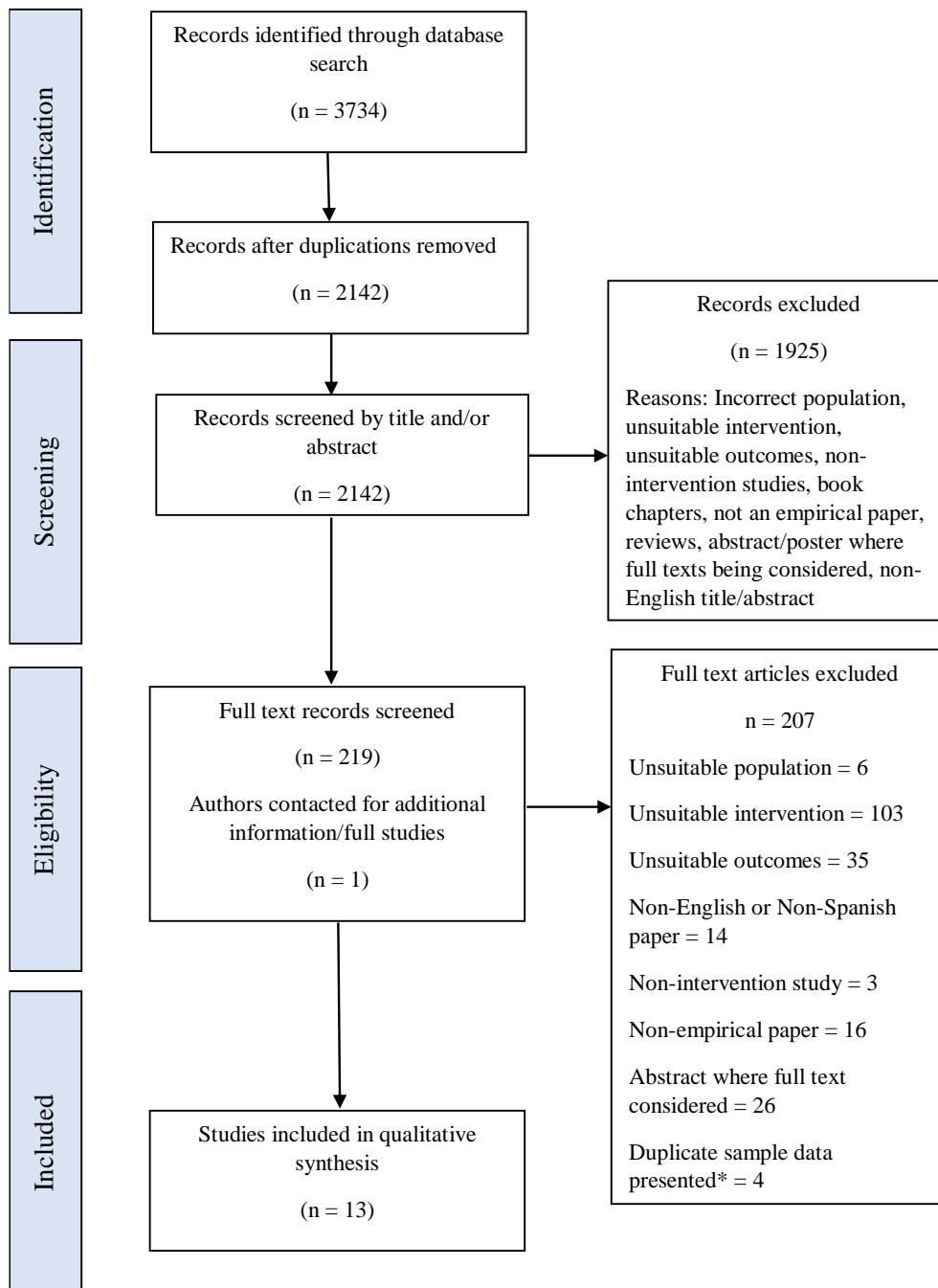


Figure 1. PRISMA Flowchart (adapted from Moher et al., 2009)

\*See Appendix 2.

Table 1. Characteristics of Studies

Study Country	Study Design	Intervention	Participants with PD - Mean age (SD) - % female	Caregivers - Mean age (SD) - % female	Duration	Follow-up	Primary Outcome Measures
		<i>Control</i>	<i>Control Characteristics</i>	<i>Control Characteristics</i>	<i>Control Duration</i>		
<b>A'Campo et al. 2009<sup>26</sup></b> Estonia, Finland, Germany, Italy, The Netherlands, Spain, UK	Pre-post	Psychosocial Education Programme Parkinson's	n = 151; 64.4 (9.2); 40	n = 137; 62.2 (11.3); 80	8 weekly 90 min sessions	none	BELA-A-k, BELA-P-k, EQ-5D (VAS), PDQ-39, SDS
<b>A'Campo et al. 2010<sup>27</sup></b> The Netherlands	RCT	Psychosocial Education Programme Parkinson's	n = 35; 65.5 (8.9); 43	n = 26; 63.4 (8.8); 65	8 weekly 90 min sessions	none	BELA-A-k, BELA-P-k, EQ-5D (VAS and Utilities), PDQ-39, SDS
		<i>Usual Care</i>	<i>n = 29; 64.2 (9.1); 48</i>	<i>n = 20; 61.5 (11.3); 60</i>			
<b>A'Campo et al. 2011<sup>28</sup></b> The Netherlands	Pre-post	Psychosocial Education Programme Parkinson's	n = 55; 68.0 (11.1); 33	n = 50; 66.6 (7.5); 36	8 weekly 90 min sessions	6 months	PDQ-39, BELA-A-k
<b>Butterfield et al. 2017<sup>29</sup></b> USA	Pre-post	Parkinson's Active Living Programme	n = 34; 66.0 (10.7); 35	n = 27	1 in-person & 6 weekly 10-20 min telephone sessions	1 month	AES-S

Study Country	Study Design	Intervention	Participants with PD - Mean age (SD) - % female	Caregivers - Mean age (SD) - % female	Duration	Follow-up	Primary Outcome Measures
		<i>Control</i>	<i>Control Characteristics</i>	<i>Control Characteristics</i>	<i>Control Duration</i>		
<b>Cash &amp; Lagerman, 2015<sup>30</sup></b>  USA	RCT	Expressive writing  <i>Neutral writing</i>	n = 15; 67.2 (7.6) overall; 50 overall  <i>n = 12</i>	n = 8  <i>n = 6</i>	3 sessions  <i>As above</i>	4 & 10 months	MAQ, BDI-II, AS, LASA, ECOG, PD-NMS, PDQ-39, ZBI, Trailmaking test A & B, ACT, DS, LNS, CVLT-II, CAR
<b>Dissanayaka et al. 2017<sup>31</sup></b>  Australia	Pre-post	CBT aimed to treat anxiety in PD	n = 17; 66.6 (7.1); 41	n = 15; 63.4 (9.7); 53	6 weekly sessions + 2 booster sessions	3 & 6 months	HAM-A, GAI, IQAD
<b>Dobkin et al. 2011a<sup>32</sup></b>  USA	RCT	CBT for depression in PD  <i>Close Clinical Monitoring</i>	n = 41; 63.7 (9.9); 39  <i>n = 39; 65.4 (11.2); 41</i>	n = 41  <i>n = 39</i>	10 weekly 60-75 min sessions + 4 caregiver sessions  <i>5 telephone call sessions over 14 weeks</i>	1 month	HAM-D
<b>Dobkin et al. 2011b<sup>33</sup></b>  USA	Uncontrolled Pilot	Telephone-based CBT for depression in PD	n = 21; 65.9 (9.3); 62	n = 21	10 x 60-90 min sessions + 4 optional caregiver telephone sessions	1 month	HAM-D



Study Country	Study Design	Intervention	Participants with PD - Mean age (SD) - % female	Caregivers - Mean age (SD) - % female	Duration	Follow-up	Primary Measures	Outcome
		<i>Control</i>	<i>Control Characteristics</i>	<i>Control Characteristics</i>	<i>Control Duration</i>			
<b>Dobkin et al. 2018</b> <sup>34</sup> USA	Uncontrolled pilot	Telephone-based CBT for depression in PD	n = 34; 62.6 (9.5); 38	n = 34	10 x 75-90 min CBT sessions OR biweekly 30-45 min informal coaching sessions	1 month	HAM-D, SF-36	
<b>Okai et al., 2013</b> <sup>35</sup> UK	RCT	CBT for ICB  <i>Waiting list with usual care</i>	n = 28; 59.3 (8.3); 32  <i>n = 17; 57.9 (9.5); 30</i>	n = 28  <i>n = 17</i>	12 weekly sessions	6 months	CGI, NPI	
<b>van der Marck et al. 2015</b> <sup>36</sup> Canada	RCT	MDT Care  <i>General Neurologist input</i>	n = 51; 65.9 (8.5); 41  <i>n = 49; 68.1 (8.8); 43</i>	n = 51  <i>n = 49</i>	8 months  <i>As above</i>	none	PDQ-39	

Study Country	Study Design	Intervention	Participants with PD - Mean age (SD) - % female	Caregivers - Mean age (SD) - % female	Duration	Follow-up	Primary Measures	Outcome
		<i>Control</i>	<i>Control Characteristics</i>	<i>Control Characteristics</i>	<i>Control Duration</i>			
<b>Wade et al. 2003<sup>37</sup></b> UK	RCCT	MDT Rehabilitation and Group Education Programme  <i>Delayed Intervention</i>	n = 53; 71.3 (8.6); 43  <i>n = 41; 70.4 (7.6); 37</i>	n = 40  <i>n = 28</i>	6 individual and group weekly sessions	4 months	PD disability questionnaire, PDQ-39, SF-36, EQ-5D, Stand- walk-sit test, Nine hole peg test, UPDRS, HADS, CSI	
<b>Rubino 2013<sup>38</sup></b> (unpublished thesis) USA	Case Series	IPT for depression in PD	n = 3; 68.3; 66	n = 3	Between 6-15 weekly sessions	1 month	HAM-D, CGI, BDI-II, SF-36, SAS-SR, MSPSS, ZBI	

SD = Standard deviation, BELA-A-k = Belastungsfragebogen Parkinson kurzversion, BELA-P-k = Belastungsfragebogen Parkinson Angehörigen kurzversion, EQ-5D = EuroQol five dimension questionnaire, VAS = Visual Analogue Scale, PDQ-39 = Parkinson's disease questionnaire (39 item), SDS = Self-rating Depression Scale, RCT = Randomised Control Trial, AES-S = Apathy Evaluation Scale-Self, MAQ = Multi-dimensional Anxiety Questionnaire, BDI-II = Beck Depression Inventory-II, AS = Apathy Scale, LASA = Linear Analogue Self-Assessment, ECOG = Everyday Cognition scale, PD-NMS = Parkinson's disease Non-Motor Symptom Questionnaire, ZBI = Zarit Burden Inventory, ACT = Auditory Consonant Trigrams, DS = Digit Span, LNS = Letter Number Sequencing, CVLT-II = California Verbal Learning Test – II, CAR = cortisol awakening response, CBT = Cognitive Behavioural Therapy, HAM-A = Hamilton Anxiety Rating Scale, GAI = Geriatric Anxiety Inventory, IQAD = Informant Questionnaire for Anxiety in Dementia, HAM-D = Hamilton Depression Rating Scale, SF-36 = Medical Outcome Study 36-item Short-Form health survey, ICB = Impulse Control Behaviours, CGI = Clinical Global Impression, NPI = Neuropsychiatric Inventory, MDT = Multi-disciplinary Team, RCCT = Randomised Crossover Controlled Trial, UPDRS = Unified Parkinson's disease Rating Scale, HADS = Hospital Anxiety and Depression Scale, CSI = Carer Strain Index, IPT = Interpersonal Psychotherapy, SAS-SR = Social Adjustment Scale Self-Report, MSPSS = Multidimensional Scale of Perceived Social Support

## *Design*

Five of the included studies were RCTs.<sup>27,30,32,35,36</sup> Control interventions included; treatment as usual,<sup>27,35</sup> a neutral writing intervention,<sup>30</sup> input from the General Neurologist,<sup>36</sup> and close clinical monitoring.<sup>32</sup> One study was a randomised controlled crossover trial including a waiting list control.<sup>37</sup> Six studies used a quasi-experimental (pre-post, single group) design<sup>26,28,29,31,33,34</sup> and one study was a case series.<sup>38</sup>

## *Participants*

*People living with PD:* All studies included participants with a confirmed diagnosis of PD (n=13). Five studies required participants to have a psychiatric diagnosis in order to meet inclusion criteria. One study required diagnosis of anxiety<sup>31</sup> and four studies required a diagnosis of depression.<sup>32-34,38</sup> One study required participants to present with clinically significant impulse control behaviours (ICB).<sup>35</sup> Sample sizes ranged from 3-151. Mean ages ranged from 59-71 years. Seven studies reported PD severity using the Hoehn and Yahr,<sup>39</sup> with means ranging from 2.0-2.4.<sup>26-28,31-33,35</sup> Two studies reported severity using the total score of the Unified Parkinson's disease Rating Scale (UPDRS)<sup>40</sup> with means ranging from 24.73-37.49.<sup>31,35</sup> Nine studies described PD duration with means ranging from 4.3-10.1 years.<sup>27-29,32-36,38</sup>

*Caregivers:* Ten studies provided detail of the involvement of caregivers in the intervention, and further information regarding caregiver input was sought from the authors of three studies.<sup>35-37</sup> Sample sizes ranged from 3-137. Four studies provided demographic information regarding the caregivers,<sup>26-28,31</sup> with mean ages ranging from 62-67 years. The caregivers' relationship to participant living with PD were described

by eight studies.<sup>26,27,29,31-34,38</sup> Relationships reported included; partner, family, friend, professional.

### *Intervention*

Four studies delivered a CBT intervention<sup>31-34</sup> and five studies delivered an intervention informed by CBT principles and/or strategies.<sup>26-29,35</sup> One study delivered an expressive writing intervention<sup>30</sup> with another delivering Interpersonal Therapy (IPT).<sup>38</sup> One study provided multi-disciplinary team (MDT) input alongside group education,<sup>37</sup> and one study provided specialist MDT which included Social Workers whose aim were to target psychosocial issues.<sup>36</sup>

Participants living with PD were primary targets of the interventions within all included studies. Three studies delivered group interventions<sup>26-28</sup> with an additional study including a group education component alongside specialist MDT input.<sup>37</sup> Five studies delivered face-to-face individual interventions.<sup>31,32,35,36,38</sup> Three studies intervention were delivered predominantly through telephone sessions.<sup>29,33,34</sup> One study which evaluated an expressive writing intervention, was self-delivered.<sup>30</sup>

Due to the variation of caregiver involvement, this was categorised in line with previous research exploring dyad-based interventions.<sup>41</sup> The caregiver involvement was classified as a dyadic intervention (participants living with PD and their caregivers attend the intervention together), co-facilitating intervention (caregiver role is to support the participant living with PD during the intervention) or individual intervention (caregiver receives the same or similar intervention to the participant

living with PD).<sup>41</sup> Within this review it was identified that seven studies delivered a co-facilitating intervention for caregivers,<sup>32-38</sup> four studies delivered individual interventions to caregiver,<sup>26-28,30</sup> and only two studies described a dyadic intervention.<sup>29,31</sup>

### ***Appraisal of Methodological Quality***

Table 2 outlines the ratings of each study across all components assessed, components were rated either ‘strong’, ‘moderate’, ‘weak’ or ‘not applicable’. Details of which can be found in Appendix 3. Only two studies by Dobkin et al.<sup>32</sup> and van der Marck et al.<sup>36</sup> received the EPHPP global rating of ‘strong’. This may be due to the methodological strength of design and quality of reporting. Compared to the other RCT studies, these two studies<sup>32,36</sup> clearly described their process of randomisation reducing selection bias, demonstrated no significant differences between groups at base line, and blinded assessors to intervention group. However, due to possible selection bias and lack of participant blinding, there is still a potential for bias within these highest rated studies. Six studies received a global rating of ‘moderate’ due to lack of blinding of both assessors and participants in four of these studies,<sup>27-29,33,35</sup> and one study experiencing more than 40% withdrawals and dropouts.<sup>37</sup> The final five studies receiving a global rating of ‘weak’ were primarily due to lack of blinding,<sup>26,31,34,38</sup> poor completion rate,<sup>26,31,34</sup> or high risk of selection bias and confounding variables.<sup>30</sup> It was also noted that three studies received a ‘weak’ rating for intervention integrity due to lack of reporting on exposure to the intervention and fidelity assessment of the intervention delivered.<sup>26-28</sup>

Table 2. Methodological Quality Appraisal Ratings

Authors (Year)	Selection Bias	Study Design	Confounders	Blinding	Data Collection Method	Withdrawals and Dropouts	EPHPP Global Rating*	Intervention Integrity	Analyses	Quality of Reporting	Generalisability
A'Campo et al. 2009 <sup>26</sup>	2	2	N/A	3	1	3	3	3	2	2	1
A'Campo et al. 2010 <sup>27</sup>	2	1	1	3	1	1	2	3	2	3	1
A'Campo et al. 2011 <sup>28</sup>	2	2	N/A	3	1	2	2	3	2	2	1
Butterfield et al. 2017 <sup>29</sup>	2	2	N/A	3	1	1	2	1	2	2	1
Cash & Lagerman 2015 <sup>30</sup>	3	1	3	2	1	2	3	2	2	2	1
Dissanayka et al. 2017 <sup>31</sup>	2	2	N/A	3	1	3	3	2	2	2	2
Dobkin et al. 2011a <sup>32</sup>	1	1	1	2	1	1	1	1	1	1	1
Dobkin et al. 2011b <sup>33</sup>	2	2	N/A	3	1	1	2	1	1	1	1
Dobkin et al. 2018 <sup>34</sup>	2	2	N/A	3	1	3	3	2	1	2	1
Okai et al. 2013 <sup>35</sup>	2	1	1	3	1	2	2	1	1	2	1
van der Marck et al. 2015 <sup>36</sup>	2	1	1	2	1	1	1	2	2	2	1
Wade et al. 2003 <sup>37</sup>	2	1	1	2	1	3	2	2	2	2	1
Rubino 2013 <sup>38</sup>	2	3	N/A	3	1	2	3	1	2	2	2

1 = Strong; 2 = Moderate; 3 = Weak; N/A = not applicable; \*EPHPP Global Rating derived from following components; selection bias, study design, confounders, blinding, data collection method, withdrawals and dropout

## ***Key Findings***

Table 3 summarises the results of both the psychological and additional outcomes reported within the studies, with effect sizes described as reported. It was not considered appropriate for effect sizes to be calculated due to heterogeneity of studies and reporting of outcomes by authors of the included studies.

### ***Psychological Outcomes***

*Depression:* Twelve of the studies assessed effectiveness of interventions on reducing depressive symptoms within participants living with PD.<sup>26,27,29-38</sup> The two RCT studies assessed as having ‘strong’ methodological strength assessed effectiveness of reducing depression, one of studies delivered a CBT intervention<sup>32</sup> and the other was a specialist MDT intervention.<sup>36</sup> Both these studies found significant reductions in depressive symptoms in the intervention group compared to the control group, alongside large effect sizes found in the one study which provided effect sizes.<sup>32</sup> Another RCT reported significant reduction in depressive symptoms in participants living with PD receiving a CBT-based intervention compared to the control group, with medium effect sizes at the 6 month follow-up.<sup>35</sup> A further three studies of quasi-experimental design with mixed methodological quality also found significant improvements in depression post intervention.<sup>29,33,34</sup> Similarly, an IPT case series reported clinically significant improvements with their two participants depressive symptoms.<sup>38</sup> All of the included studies which required participants living with PD to have a diagnosis of a depressive disorder reported significant improvements in depressive symptoms.

The remaining four studies found no significant changes post intervention.<sup>26,27,30,31</sup> The authors of two of these studies used the Self-rating Depression Scale which is yet to be validated, and they noted that there may have been a floor effect due to limited depressive symptomology at baseline.<sup>26,27</sup> Alongside this, three of the studies which did not report any significant changes in depression had a global rating of ‘weak’ methodological quality.<sup>26,30,31</sup> Therefore, poor outcome measures, selection bias or high attrition rate, may have impacted on the outcomes reported.

Caregiver depression was evaluated in four studies delivering either CBT, CBT informed interventions or IPT.<sup>26,27,31,38</sup> Authors of these studies similarly used unvalidated outcome measures and/or demonstrated areas of methodological weakness, of which none demonstrated any significant reductions in depression.<sup>26,27,31,38</sup>

*Anxiety:* Seven studies reported outcomes of anxiety for participants living with PD.<sup>30-35,37</sup> Only one of the studies with ‘strong’ methodological quality, assessed effectiveness of their CBT intervention on reducing anxiety in people living with PD and found significant improvements in anxiety at the end of the intervention compared to the control group.<sup>32</sup> This was also maintained at the four-week follow-up.<sup>32</sup> A further four studies delivering CBT or CBT-informed interventions demonstrated significant improvements post intervention,<sup>31,33-35</sup> however, two of these studies received ‘weak’ rating for methodological quality.<sup>31,34</sup> Two studies reported no significant improvement with anxiety compared to control groups.<sup>30,37</sup> Neither of these two studies delivered CBT or CBT-informed interventions, and one of these studies



did not use an anxiety outcome measure demonstrated to be valid and reliable outcome measures of anxiety in people living with PD.<sup>30</sup> Only one study reported outcomes of anxiety for caregivers, with no significant changes post intervention, however, this may be due to the high rate of dropouts and small sample size.<sup>31</sup> Overall, dyad-based interventions which are derived from CBT appear to demonstrate effectiveness in reducing anxiety in people living with PD, whilst there is no quality research to draw conclusions regarding the effects for caregivers.

*Quality of Life:* Twelve studies assessed quality of life pre and post intervention for people living with PD.<sup>26,27,29-38</sup> All studies used at least one measure of quality of life which has demonstrated validity and reliability within people living with PD. Two RCTs with the strongest rating of methodological quality, a CBT intervention and a specialist MDT intervention, all found significant improvements in quality of life.<sup>32,36</sup> Three studies which delivered CBT-informed intervention found significant improvements,<sup>27,29,34</sup> with two of these studies being rating as ‘moderate’ for their methodological quality.<sup>27,29</sup> The further five studies found no significant improvements in quality of life for participants living with PD.<sup>26,30,31,33,37</sup> The case series for IPT observed worsening of quality of life within one of the two participants who completed the IPT intervention.<sup>38</sup> Considering that PD worsens with time, and research suggests that quality of life is associated with severity of PD,<sup>42,43</sup> establishing the effect of an intervention without a control group for comparison is challenging.

Three studies used the Eurqol-5d (EQ-5D) questionnaire,<sup>44</sup> where authors described it as a health-related quality of life measure. Research suggests that the EQ-5D assesses

perceived health more closely than quality of life.<sup>45</sup> Therefore, the results of the EQ-5D will be explored separately from the quality of life results previously outlined. One study used the EQ-5D with both participants living with PD and their caregivers, finding no significant difference post intervention.<sup>37</sup> Correspondingly, two other studies found no significant changes for caregivers on the EQ-5D following the intervention.<sup>26,27</sup> Thereby, suggesting that psychosocial interventions for people living with PD and their caregivers may not improve perceived health for both populations.

*Caregiver Specific Outcomes:* Five studies assessed caregiver burden using the valid and reliable Zarit Burden Inventory<sup>46</sup> and utilised a variety of designs and interventions.<sup>29-31,35,38</sup> Four of the studies found no significant improvements and the further study observed improvements at post intervention which were not maintained at follow-up.<sup>31</sup> One study assessed caregiver psychological outcomes using the Caregiver Strain Index,<sup>47</sup> reporting no significant improvements between groups.<sup>36</sup> Three studies evaluated caregiver distress, using the Caregiver Distress Scale (CDS). The CDS was validated by an author of these studies and has not yet been assessed independently.<sup>32-34</sup> Of the studies using the CDS, two found no significant improvements<sup>32,33</sup> and one did find significant improvements.<sup>34</sup> In summary, evidence would suggest that psychosocial interventions delivered to people living with PD and their caregivers do not lead to reduced burden and/or distress in the caregivers. However, considering the heterogeneity of the interventions, designs, quality of the studies and outcome measures across the studies, further research of high-quality is required to draw any definite conclusions.

*Additional Psychological Outcomes:* Three studies explored apathy within participants living with PD.<sup>29-31</sup> One study used the Apathy Evaluation Scale-Self,<sup>48</sup> which found significant improvements within groups at post intervention and at one-month follow-up.<sup>29</sup> Two studies used the Starkstein Apathy Scale,<sup>49</sup> neither of which found any significant improvements post intervention.<sup>30,31</sup>

Two studies of ‘moderate’ quality delivering CBT interventions assessed coping styles in participants living with PD. Both studies found significantly greater use of positive reframing as a coping style following the intervention, with no significant change in the use of problem-focused coping.<sup>32,33</sup> Three studies evaluated negative thoughts of participants with PD. The RCT delivering individual CBT found no significant difference between groups post intervention and at follow-up<sup>32</sup> and the two quasi-experimental studies delivering CBT through telephone found significant reduction in negative thoughts.<sup>33,34</sup>

Psychosocial functioning was assessed in both participants living with PD and caregivers. When assessed in participants living with PD, two out of three studies assessing psychosocial functioning found significant improvements following interventions, however, the CBT intervention<sup>26</sup> showed poor methodological quality compared to the specialist MDT intervention.<sup>36</sup> Within participating caregivers, two of three studies found significant improvements of psychosocial functioning in caregivers following participating in a parallel CBT-informed caregiver group intervention.<sup>26,27</sup>

One RCT assessed general psychiatric co-morbidity, finding significant reductions in both caregivers and participants living with PD within the CBT-informed intervention group compared to the control group at the 6-month follow-up.<sup>35</sup> The primary aim for this study was to reduce impulse control behaviours (ICB) within participants living with PD. However, at time of delivering the intervention there were no known validated measures for ICB.<sup>35</sup> As a result, the authors developed a measure specifically for the study, reporting significant reductions in ICB in the intervention group compared to the control group at follow-up.<sup>35</sup>

For each additional psychological outcome assessed across the dyad-based psychosocial interventions included within this review, very few studies overlap in choice of outcomes and present with mixed findings. Some of studies used different outcome measures to assess the same psychological outcomes or used unvalidated measures for this population, therefore, limiting the comparison of the findings reported across these studies. Alongside this, many of the studies are of poor methodological quality. Therefore, caution is required when drawing conclusions regarding the effectiveness of dyad-based intervention on the additional psychological outcomes outlined.

### *Additional Outcomes*

Alongside a variety of psychological outcomes measured within the included studies, this review found that there were many additional outcomes assessed. Two studies assessed perceived inferential feedback using the Social Feedback Questionnaire, this measure was developed by an author of these studies and has yet to be independently

validated.<sup>32,33</sup> Authors reported no significant changes post intervention and at follow-up for both these studies.<sup>32,33</sup> Two studies measured both social functioning and quality of social support.<sup>35,38</sup> Measures used to assess these outcomes differed in the RCT and case series. Significant improvements were only found for social functioning for participants living with PD in the RCT,<sup>35</sup> and no significant changes were observed in caregivers when assessed.<sup>35</sup>

Four studies assessed motor functioning, two of which were RCT's which demonstrated strong methodological quality compared to the other studies.<sup>32,36</sup> The authors of these higher quality studies found a significant improvement of motor functioning in the intervention group compared to the control group.<sup>32,36</sup> It was unclear how long this effect lasted as no follow-up data were available for these studies. A further study found a significant improvement within group of motor functioning, which was maintained at the 3-month and 6-month follow-up.<sup>31</sup> The final study assessing motor functioning, found no significant changes for the intervention group compared to the control group.<sup>37</sup> Outcome measures used to measure motor functioning varied across these studies, however, all had been previously validated for people living with PD.<sup>50,51</sup>

The overall severity of symptoms of PD was also assessed by several included studies. Two studies used either the UPDRS or Movement Disorder Society UPDRS total score, with one reporting significant improvement within group at post intervention and 3-month follow-up but not at 6-month follow-up,<sup>31</sup> the other study reported significant improvements for the intervention group compared to the control group at

post intervention.<sup>36</sup> Another study used the Parkinson's disease disability questionnaire to assess symptom severity and found that there was no difference between control and intervention groups post intervention, noting that all participants scores had worsened over the assessment period which is in keeping with the nature of a degenerative disease.<sup>37</sup>

The effectiveness of interventions on sleep of participants living with PD was assessed by three studies. These studies used outcome measures which have been validated within the general population, however, are yet to be validated within a PD population (Pittsburgh Sleep Quality Index and Insomnia Severity Index). All studies assessing sleep found no significant changes following a CBT intervention.<sup>32,33,34</sup>

Another study assessed common non-motor symptoms of PD using the valid and reliable Parkinson's disease Non-Motor Symptom Questionnaire,<sup>3</sup> and they reported no significant changes in these symptoms post intervention.<sup>30</sup> This same study also assessed cortisol awakening response of participants living PD and their caregivers, and a multitude of cognitive abilities using numerous outcomes measures for participants living with PD (e.g. Everyday Cognition scale, California Verbal Learning Test – II, Montreal Cognitive Assessment, Standardized Mini Mental State Examination, Parkinson's disease Cognitive Rating Scale, Informant Questionnaire on Cognitive Decline in the Elderly), on which there were no significant differences between control and interventions group at follow-up.<sup>30</sup>

In summary, a wide range of additional outcomes were assessed across the included studies. Symptoms of PD, both motor and non-motor, were the most frequently assessed outcomes. There is mixed evidence on the effectiveness of the interventions on these outcomes. In addition, very few studies evaluated additional outcomes for caregivers, which may have been due to people living with PD being the target of the interventions.

Table 3. Summary of Study Results

Study	Participants living with PD (n)	Caregiver (n)	Participants living with PD Psychological Outcomes [effect size]	Caregivers Psychological Outcomes [effect size]	Participants living with PD Additional Outcomes [effect size]	Caregivers Additional Outcomes [effect size]
	<i>Control (n)</i>	<i>Control (n)</i>				
<b>A'Campo et al. 2009<sup>26</sup></b>	151	137	Sig. improvement in Psychosocial problems*; No sig. difference for depression and QoL	Sig. improvement in Psychosocial problems*; No sig. difference for depression	N/A	No sig. difference in health state
<b>A'Campo et al. 2010<sup>27</sup></b>	35 29	26 20	Sig. difference (in favour of intervention group) for QoL*; No sig. difference between groups for depression and psychosocial problems	Sig. difference (in favour of intervention group) for psychosocial problems**; No sig. difference for depression	N/A	No sig. difference between groups in health state
<b>A'Campo et al. 2011<sup>28</sup></b>	55	50	No sig. difference for QoL from baseline to 6m follow up.	No sig. difference for psychosocial problems from baseline to 6m follow up	N/A	N/A
<b>Butterfield et al. 2017<sup>29</sup></b>	34	27	Sig. improvement for apathy**, depression** and QoL*	No sig. difference for caregiver burden	No sig. difference for ADL	N/A



Study	Participants living with PD (n)	Caregiver (n)	Participants living with PD Psychological Outcomes [effect size]	Caregivers Psychological Outcomes [effect size]	Participants living with PD Additional Outcomes [effect size]	Caregivers Additional Outcomes [effect size]
	<i>Control (n)</i>	<i>Control (n)</i>				
<b>Cash &amp; Lagerman 2015<sup>30</sup></b>	15 12	8 6	No sig. difference between groups for apathy, anxiety, depression and QoL	No sig. difference between groups for caregiver burden	No sig. difference between groups for non-motor symptomology, CAR, and all cognitive performance measures	N/A
<b>Dissanayaka et al. 2017<sup>31</sup></b>	17	15	Sig. improvement for anxiety** (HAM-A measure only) at all time points; No sig. difference for anxiety (GAI & IQAD), depression, apathy and QoL	Sig. improvement for caregiver burden* at post intervention (not maintained at 3m & 6m follow up); No sig. difference for anxiety and depression	Sig. improvement in PD severity* (MDS-UPDRS total, motor and non-motor) at post intervention and 3m follow up; Sig. improvement on PD specific cognitive function measure* at all time points; No sig. difference for generic and informant cognitive functioning measures	N/A
<b>Dobkin et al. 2011a<sup>32</sup></b>	41 39	41 39	Sig. difference (in favour of CBT) for depression**[HAM-D d = 1.59; BDI-II d = 1.1], anxiety**[d = .98], QoL**[d = .81] and coping* [BC-PF d = .80]. No sig. difference for negative thoughts	No sig. difference between groups for caregiver burden	Sig. difference (in favour of CBT) for PD symptom rating and motor functioning*. No sig. difference for sleep and social support	N/A

Study	Participants living with PD (n)	Caregiver (n)	Participants living with PD Psychological Outcomes [effect size]	Caregivers Psychological Outcomes [effect size]	Participants living with PD Additional Outcomes [effect size]	Caregivers Additional Outcomes [effect size]
	<i>Control (n)</i>	<i>Control (n)</i>				
<b>Dobkin et al. 2011b</b> <sup>33</sup>	21	21	Sig. improvements for anxiety**[d = 1.09], depression**[HAM-D d = 1.21; BDI d = 1.13], negative thoughts*[d = .42] and coping* [BC-PR d = .88; BC-PF d = .54]. No sig. difference for QoL	No sig. difference for caregiver burden	No sig. difference for sleep and social support	N/A
<b>Dobkin et al. 2018</b> <sup>34</sup>	34	34	Sig. improvements for anxiety**[d = 1.65], depression**[Ham-D d = 2.15; BDI-II d = 1.18], QoL** [d = .72] and negative thoughts**[d = .73]	Sig. improvements for caregiver burden** [CDS d = .40]	Sig. improvements for sleep**, social functioning** [unclear which measure d= .80] and physical functioning** [unclear which measure d = 51]	N/A
<b>Okai et al., 2013</b> <sup>35</sup>	28 17	28 17	Sig. difference (in favour of CBT) at 6-month follow-up for neuropsychiatric disturbances* [ $n_p^2 = .12$ ], social adjustment** [ $n_p^2 = .32$ ], anxiety* [ $n_p^2 = .18$ ], depression** [ $n_p^2 = .31$ ], ICB* [ $n_p^2 = .12$ ], general psychiatric comorbidity* [ $n_p^2 = .38$ ]	Sig. difference (in favour of CBT) for general psychiatry comorbidity* [ $n_p^2 = .12$ ]; No sig. difference between groups for caregiver burden and neuropsychiatric disturbances	No sig. difference between groups for marital relationship quality	No sig. difference between groups for marital relationship quality

Study	Participants living with PD (n)	Caregiver (n)	Participants living with PD Psychological Outcomes [effect size]	Caregivers Psychological Outcomes [effect size]	Participants living with PD Additional Outcomes [effect size]	Caregivers Additional Outcomes [effect size]
	<i>Control (n)</i>	<i>Control (n)</i>				
<b>van der Marck et al. 2015<sup>36</sup></b>	51 49	51 49	Sig. difference (in favour of MDC) for depression**, psychosocial functioning* and QoL*	No sig. difference between groups for caregiver burden	Sig. difference (in favour of MDC) for PD symptomology (UPDRS total* and motor functioning*); No sig. difference for levodopa equivalent dose	N/A
<b>Wade et al. 2003<sup>37</sup></b>	53 41	40 28	No sig. difference between groups on anxiety, depression and QoL	No sig. difference between groups for caregiver burden and health-related QoL	Sig. difference (in favour of MDC) for mobility*; No sig. difference between groups for health status and PD symptomology	N/A
<b>Rubino 2013<sup>38</sup></b>	3	3	Clinically significant reduction in depression and maintained at 1-month follow-up in participants who completed intervention (n=2)	No clinically significant reductions in caregiver burden and depression.	No clinically sig. difference in social support, social adjustment, and QoL.	N/A

\*p<0.05 \*\*p<0.01, QoL = Quality of Life, ADL = acts of daily living, CAR = cortisol awakening response, HAM-A = Hamilton Anxiety Rating Scale, GAI = Geriatric Anxiety Inventory, IQAD = Informant Questionnaire for Anxiety in Dementia, MDS-UPDRS = Movement Disorder Society Unified Parkinson's disease Rating Scale, CBT = Cognitive Behavioural Therapy, HAM-D = Hamilton Depression Rating Scale, BDI-II = Beck Depression Inventory-II, BC-PF = Brief COPE (Problem focused subscale), BC-PR = Brief COPE (Positive reframing subscale), CDS = Caregiver Distress Scale, ICB = Impulse Control Behaviours, MDC = Multi-disciplinary Care, UPDRS = Unified Parkinson's disease Rating Scale

## **Discussion**

This review aimed to evaluate the effectiveness of psychosocial interventions as per the research questions, where both people living with PD and their caregivers are involved in the intervention, on psychological and any additional outcomes reported.

In summary, this review indicated mixed support for the effectiveness of dyad-based psychosocial interventions upon the outcomes of participants living with PD, and limited evidence to suggest benefits for caregivers. The majority of included studies reported significant improvements on at least one psychological outcome for participants living with PD. However, due to the heterogeneity of outcomes reported, drawing conclusions on the effectiveness of the interventions on each psychological outcome assessed was limited. CBT or CBT-informed interventions were the most prominent dyad-based psychosocial intervention delivered, and demonstrated effectiveness in reducing anxiety symptoms in people living with PD. Similarly, dyad-based psychosocial interventions which were specifically designed for people living with PD and an additional diagnosis of a psychiatric disorder all reported significant improvements in outcomes designed to assess reductions in symptoms of the psychiatric disorders. Taking in to consideration the majority of people living with PD presented with moderate PD, alongside the small sample sizes, caution should be taken when generalising the findings of these studies to the greater population of people living with PD and their caregivers.

Dyad-based psychosocial interventions which were designed to target psychiatric disorders in people living with PD, all showed effectiveness in relation to symptoms of the target psychiatric disorder. All four studies which were designed for people living with PD and a diagnosis of a depressive disorder, reported significant improvements in depressive symptoms following the interventions. This was demonstrated across studies regardless of the type or delivery of the intervention. It may be due to the interventions focusing on targeting known maintaining factors for depressive disorder that results in the improvements. Due to limited studies which were designed for other psychiatric disorders, alongside the poor methodological quality of these studies, further research would be required in order to understand whether diagnosis specific interventions are more beneficial than a transdiagnostic intervention for people living with PD. Notwithstanding, in line with previous research,<sup>4,13</sup> this review provides further evidence of the effectiveness of psychosocial interventions for depression in people living with PD.

Alongside depression, quality of life was one of the most frequent outcomes measured across the dyad-based psychosocial intervention studies included within this review. Many of the studies demonstrated improvements in quality of life for people living with PD, where others found no significant change. Quality of life is typically defined by the World Health Organisation as "a state of complete physical, mental, and social well-being not merely the absence of disease".<sup>52(p1)</sup> Whilst the culture and values systems an individual lives within are required to be taken into consideration when understanding an individual's quality of life.<sup>52</sup> The broadness and complexity of the construct of quality of life appears to be reflected within this review, which found

varied outcome measures were used across studies to assess quality of life in participants. The need to consider the many mental, social and physical factors of quality of life may also account for the broad range of additional outcome measures included across the studies, as these additional factors could contribute to an individual's perceived quality of life e.g. sleep, social functioning, quality of relationships. As a result, a single outcome measure is restricted in how it can fully capture the quality of life of every individual, due to the subjective nature of this construct. Studies within this review may not capture all aspects of participants lives which they perceive to be relevant for better quality of life and could account for the mixed findings of this review.

It is also important to contemplate the nature of PD when considering quality of life outcomes. Previous research has found that severity of illness is a main predictor for quality of life.<sup>42,43</sup> Considering the nature of PD as a degenerative condition, it would therefore be expected that over time, quality of life deteriorates as the disease progresses. As reported, the majority of studies found either improvements or no significant changes in quality of life. Although no conclusive evidence was drawn from this review to suggest that dyad-based psychosocial interventions improve quality of life for people living with PD, it may be that these interventions may at least reduce the expected deterioration in quality of life. However, to establish whether this may be the case, further studies should include control groups and longer follow-up periods in order to establish whether dyad-based psychosocial interventions may either improve quality of life or slow the deterioration of quality of life as the disease progresses.

Similarly, when exploring additional outcomes assessed by the studies within this review, many assessed symptoms of PD using a wide range of outcome measures. As previously discussed, due to the nature of the disease it would be expected that symptoms of PD would continue to worsen over time. Yet, many studies either reported improvements or no significant changes following the intervention, in relation to both motor and non-motor symptoms of PD. Alongside a need to control for the disease progression, better consistency of outcome measures would be required to allow a valid comparison across studies.

This review found very limited evidence regarding the effectiveness of dyad-based psychosocial interventions on caregiver outcomes. There was an observed lack of information gathered by studies in relation to caregiver demographics to account for confounding variables, alongside limited reporting on the involvement and adherence of caregivers to psychosocial interventions. Considering PD is not a discriminatory disease,<sup>53</sup> it would be expected that caregivers may also be a diverse population e.g. ethnicity, socioeconomic status, gender etc. Therefore, being able to account for variations within the population may help identify whether there are certain subgroups which may either benefit, or not, from participating in a dyad-based psychosocial intervention.

This review also found that caregivers tend to be included in psychosocial interventions in order to act as co-facilitators, in line with previous research.<sup>10</sup> This highlights that although researchers recognise the potential benefit of included caregivers in psychosocial interventions for people living with PD, the interventions

may not be designed with the needs of the caregivers at the forefront. This may result in limited consideration of the varied needs that caregivers may experience. On the other hand, due to the broad needs of caregivers (e.g. financial, social, emotional), psychosocial interventions may be limited in how they can address all these factors.

One factor which could account for challenges in addressing the broad needs of caregivers, which was overlooked by many authors of included studies, is the relationship between caregivers and their care receivers. A spouse providing care to their partner may face different challenges compared to a child or friend. For example, some PD symptoms, such as sexual dysfunction and cognitive impairment, contribute to reduced marital satisfaction.<sup>54,55</sup> However, participants raising concerns about intimate marital issues may be more challenging within heterogeneous samples of caregivers or within group settings. Future studies should consider how best to tailor interventions to the needs of participating caregivers, whilst identifying whether they are more effective for homogeneous groups of caregivers.

This review does demonstrate that caregivers participating in dyad-based CBT or CBT-informed psychosocial interventions do not experience any detrimental effects. Within clinical practice it is not uncommon for people living with physical conditions to rely on the support of caregivers in order to attend health appointments. Therefore, involving caregivers may support the adherence of people living with PD to attending effective psychosocial interventions without any detriment to caregivers.



The most common types of dyad-based psychosocial intervention identified within this review were CBT or interventions informed by CBT principles and strategies. In line with previous reviews,<sup>5,13,14</sup> CBT derived interventions demonstrated significant improvements of psychological outcomes post intervention for people living with PD, especially in reducing symptoms of anxiety.<sup>31-35</sup> Alongside this, the CBT informed interventions within this review were delivered over 6-12 weeks. As a result, this review demonstrates that CBT derived dyad-based interventions can be appropriately adapted for people living with PD whilst being delivered within a limited time frame. Considering the restricted resources available within public funded health services, interventions derived from CBT for people living with PD may provide an economical and effective option within clinical practice.

Overall, the methodological quality of the included studies was low. Although there were two studies which were identified to be of greater methodological quality, all studies were assessed to have at least one area for potential risk of bias. The main cause of concern contributing to poor quality were the design of the studies. The majority were quasi-experimental designs, resulting in risk of bias due to lack of blinding ability to account for confounding variables. Although the majority of outcome measures selected within the included studies were valid and reliable for the population, some studies also included measures developed by the authors and had not yet been independently assessed for people living with PD. The use of potentially unreliable measures may not measure the intended outcome and could account for the lack of significant effects within the outcomes. Overall, the quality appraisal of included studies highlights the need for further research of higher quality to draw definite

conclusions regarding the effectiveness of dyad-based psychosocial interventions within people living with PD and their caregivers.

### ***Strengths and Limitations of Review***

This review identified thirteen papers through searching multiple databases. Although the research criteria to include caregiver outcomes within the interventions may have potentially reduced the number of articles included, the sample attained was in line with similar reviews with people living with PD.<sup>5,13</sup> The inclusion of grey literature and no date restrictions within the search was identified as a strength, as it reduced the likelihood of publication bias. Conversely, due to limited resources only English and Spanish language studies were included.

This review also aimed to identify studies which included interventions which have a growing field of research within health (e.g. CFT, ACT) albeit failing to identify any studies which met the inclusion criteria. It may be due to the strict exclusion criteria which prevented the inclusion of exercise therapies, that exercise interventions containing components of third-wave therapies may have resulted in the lack of these interventions being included.

It should also be noted that this review did not specify that dyad-based psychosocial interventions required all participants living with PD to include their caregivers within the interventions. Due to this being omitted from the criteria, alongside the limited demographic information regarding caregivers presented within the studies, it was not possible to establish the difference between dyadic participation compared to participants who attended alone. However, it was decided that this should not be part

of the criteria in order to reflect clinical practice, as there are incidences when participants living with PD and/or caregivers attend on their own, whether this may be due to commitments or preferences.

### ***Implications for Research***

The review has demonstrated that research of greater methodological quality is needed, whilst highlighting the importance of control groups and longer follow-up to account for disease progression and the impact this could have on reported outcomes. This study also highlights that future studies should utilise outcome measures that have demonstrated validity and reliability within people living with PD and caregivers, whilst developing consistency of chosen measures across future studies to allow for valid comparisons. As acknowledged, a range of outcomes may be required in future research to assess effectiveness of dyad-based interventions to account for the range of effects PD can have on both those experiencing the disease and their caregivers.

This review also highlights the continued lack of consideration of the unique needs of caregivers within psychosocial interventions.<sup>10</sup> Future studies require more detailed reporting regarding participating caregivers, to identify whether there are subgroups of caregivers who benefit from participating in a dyad-based psychosocial intervention. Information regarding differences between participants who participate as a dyad compared to alone could potentially identify subgroups of participants better suited for dyad-based psychosocial interventions.

## ***Conclusions***

In line with previous research, there appears to be a role for dyad-based psychosocial interventions for people living with PD. CBT and CBT-informed interventions continue to dominate this area of research, demonstrating effectiveness in improving psychological outcomes for people living with PD, especially reducing symptoms of anxiety. Dyad-based psychosocial interventions targeted for psychiatric disorders such as depression, also demonstrate effectiveness for people living with PD. However, as this review has highlighted mixed and sparse evidence of dyad-based psychosocial interventions on additional outcomes for people living with PD and reported outcome for caregivers, further research is still required within this area.

## ***Clinical Messages***

- Overall, dyad-based psychosocial interventions can produce statistically significant effects on psychological outcomes for people living with PD.
- Dyad-based psychosocial interventions delivered to people living with PD and a diagnosed depressive disorder, may reduce symptoms of depression.
- CBT derived interventions demonstrate effectiveness at reducing symptoms of anxiety in people living with PD.
- Limited evidence was found to support the effectiveness of dyad-based psychosocial interventions for caregivers.
- Further high-quality research is required, considering both traditional psychosocial interventions and third-wave interventions (e.g. ACT, CFT).

### ***Contributors***

The study was initiated and designed by LH, who conducted database searches, identified studies, completed data extraction, undertook quality appraisal, and wrote the manuscript. KG undertook quality appraisal. AG supervised the design and identification of relevant studies and reviewed the manuscript.

### ***Conflicts of interest***

The authors declare there is no conflict of interest.

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## Chapter 2. Empirical Paper<sup>1</sup>

### **Psychological adjustment in people living with Parkinson's disease and their caregivers: the role of coping, illness beliefs and self-compassion**

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<sup>1</sup> This review has been written in accordance with submission guidelines for the journal *Psychology & Health*, however, margins and tables have followed the guidance for thesis submission. A copy of the guidelines can be found in Appendix 4.

## **Abstract**

**Objective:** This study extended previous research examining the relationship between illness beliefs and coping with psychological adjustment (in terms of anxiety, depression and quality of life) in people living with Parkinson's disease (PD) and caregivers, whilst developing research into the role of self-compassion within this process.

**Design:** A cross-sectional survey design with participants living with PD (N=66) and their caregivers (N=24) was utilised.

**Main Outcome Measures:** Brief COPE, Brief-Illness Perception Questionnaire, Self-Compassion Scale, Hospital Anxiety and Depression Scale, Parkinson's disease Questionnaire 8-item and Adult Carer Quality of Life Questionnaire.

**Results:** Within a sample of people living with mild PD, greater coping responses and lower self-compassion were associated with greater levels of anxiety, perceiving PD to result in severe consequences was associated with greater levels of depression, and holding a strong illness identity was associated with poorer quality of life. Within the sample of caregivers, no independent predictors of psychological adjustment outcomes were found.

**Conclusion:** Illness beliefs, coping responses and self-compassion may be associated with outcomes of psychological adjustment in people living with PD. Further research of a larger and more representative sample is required to establish the role of illness beliefs, coping responses and self-compassion with psychological adjustment in people living with PD and their caregivers.

**Key words:** Parkinson's disease, caregivers, psychological adjustment, illness representations, self-compassion

## **Introduction**

Parkinson's disease (PD) is the second most prevalent neurodegenerative disease after Alzheimer's disease. The prevalence is expected to continue to increase with rising life expectancy and resulting in a growing number of caregivers supporting those affected (Pringsheim et al., 2014). People living with PD can experience motor symptoms including tremors, stiffness and slow movement predominantly due to the death of dopamine producing cells within the brain (Bellucci et al., 2016). PD motor symptoms can also be accompanied by non-motor symptoms, including insomnia, apathy, fatigue and cognitive impairment (Martinez-Martin et al., 2013).

Although advances in research have led to developments in pharmacological and surgical interventions which may manage these symptoms, there is no known cure. Due to the chronic and degenerative nature of the disease, symptoms worsen over time. Deterioration can result in wide ranging difficulties from loss in mobility, cognitive impairment, to difficulty communicating (Hsu et al., 2018). As a result, people living with PD may require increasing support from others. In many cases, it may be partners and family that provide care to those living with PD (Leiknes, Lien & Severinsson, 2015). Living with PD impacts the quality of life (QoL) for both those with the disease and their caregivers (Dauwerse, Hendriks, Schipper, Struiksma, & Abma, 2014; Kudlicka, Clare & Hindle, 2013). Therefore, the ability to cope and adjust over the journey of the disease would be beneficial for both people living with PD and caregivers.

Psychological adjustment is the psychological processes that people undertake when responding to chronic illness (Dekker & de Groot, 2018). The Common Sense Model (CSM) is an established approach to understand how people adjust to living with chronic illness (Leventhal, Phillips, & Burns, 2016). Developed by Leventhal and colleagues, the CSM proposes that beliefs people hold about illness guide their understanding and coping in relation to the illness. These representations of illness dictate coping actions, and as a result determine health outcomes such as psychological wellbeing and QoL. The following are the core ‘illness beliefs’ proposed by the model to be associated with health outcomes; ‘illness identity’ (attributing symptoms experienced to the illness), ‘consequences’ (impact of illness on life), ‘treatment control’ (whether treatment will help), ‘personal control’ (having control over the illness), ‘illness coherence’ (understanding of the illness), ‘timeline’ (how long the illness will last), and ‘emotional representations’ (emotional impact of the illness) (Hurt et al., 2014; Leventhal et al., 2016).

Over the last decade, a small number of studies have explored the relationship between PD illness beliefs and indicators of psychological adjustment. A prospective study of people with PD by Evans and Norman (2009) found that illness beliefs of ‘personal control’, ‘emotional representations’ and ‘consequences’ were associated with higher levels of psychological distress (in terms of anxiety and depression). Only some of the measured illness beliefs were associated with psychological distress, and it may be that there is an overlap between the subscale of ‘emotional representation’ and the outcomes of anxiety and depression. Therefore, this study has provided limited support to the extent illness beliefs are associated with psychological adjustment.



More recent studies have continued to explore the association between illness beliefs and outcomes of psychological adjustment, with varied findings. A cross-sectional study by Simpson, Lekwuwa and Crawford (2013) found that psychological outcomes were associated with the illness belief of 'illness cause' and 'illness coherence'. Simpson et al. (2013) argued that the lack of consensus in illness belief predictors reported in their study and that of Evans and Norman (2009), may be due to Evans and Norman not testing the illness beliefs against more established predictors. Further research by Hurt et al. (2014) found that holding a strong 'illness identity' and negative 'emotional representations' were associated with poor psychological wellbeing (in terms of anxiety and depression). They also found that illness beliefs of 'illness identity', 'consequences', 'cyclical timeline', and 'illness coherence' were associated with poor QoL. This research suggests that different illness beliefs may be associated with different outcomes of psychological adjustment, whilst contributing to the inconclusiveness of which illness beliefs are of importance in psychological adjustment in people living with PD.

It should also be noted that none of the previous research discussed has explored the relationship between illness beliefs and psychological adjustment in caregivers (Evans & Norman, 2009; Hurt et al., 2014; Simpson et al., 2013). The illness beliefs caregivers have in relation to their care receivers' illness has been explored in other neurodegenerative diseases, such as illness beliefs of 'timeline' and 'consequences' being associated with QoL in caregivers of people living with Huntington's disease (Kaptein et al., 2007). It is important to consider that every illness has its own

challenges, therefore, it would be beneficial to explore how caregivers adjust to supporting their care receiver living with PD.

While there is limited research investigating the role of illness beliefs within psychological adjustment of caregivers, recent research has found that coping behaviours are predictors of psychological adjustment in both people living with PD and caregivers. A cross-sectional survey by Navarta-Sánchez et al. (2016) demonstrated that better psychological adjustment in people living with PD and caregivers was associated with having a greater number of coping responses. When considering the clinical implications of these findings, psychosocial interventions providing coping strategies may be beneficial for both people living with PD and their caregivers. Research has indicated that psychosocial interventions, predominantly Cognitive Behavioural Therapy (CBT), may be beneficial for people living with PD (Yang, Sajatovic, & Walter, 2012). Considering the role of cognitions and coping strategies in psychological adjustment, it is unsurprising that CBT may be beneficial for those living with PD. This is because CBT aims to help people learn helpful behavioural and cognitive strategies, including cognitive restructuring addressing unhelpful thoughts and beliefs. Yet, there is very limited evidence for interventions that help caregivers in adjusting to PD (see Chapter 1). Therefore, further research is required to better understand which factors contribute to psychological adjustment in both people living with PD and caregivers to inform how health professionals can best support them.

There has been growing research within health exploring the relationship between self-compassion and psychological wellbeing. Compassion is described as ‘a sensitivity to suffering in self and others, with a commitment to try to alleviate and prevent it’ (Gilbert, 2014, p19). Furthermore, self-compassion is the compassion which you act towards yourself when faced with adversity (Terry & Leary, 2011). It has been established within non-clinical populations that those with greater self-compassion present with less psychological distress (Pinto-Gouveia, Duarte, Matos, & Fráguas, 2013). Whilst in older people with poorer health, those who respond self-compassionately to their difficulties perceive themselves to have greater well-being (Allen, Goldwasser, & Leary 2011).

Within populations of people living with long-term health conditions, people with self-compassion present with less psychological distress, and better QoL (Kenefick, 2016; Pinto-Gouveia et al., 2013; Wren et al., 2012). Greater self-compassion may also be associated with less psychological distress in caregivers. For example, a study of couples facing lung cancer found that less self-compassion was associated with greater psychological distress in both people living with cancer and their partners (Schellekens et al., 2017). Therefore, it would be important to consider what role self-compassion has in psychological adjustment to PD for people living with PD and their caregivers.

### ***Aims***

This study aimed to extend previous research examining the relationships between illness beliefs and coping with the psychological adjustment of people living with PD

and their caregivers, whilst developing research in to the role of self-compassion. As a result, this study addressed the following questions:

- Which illness beliefs are associated with psychological adjustment (in terms of depression, anxiety and QoL) in people living with PD and their caregivers?
- Are greater number of coping responses associated with better psychological adjustment (in terms of depression, anxiety and QoL) in people living with PD and their caregivers?
- Is self-compassion associated with better psychological adjustment (in terms of depression, anxiety and QoL) in people living with PD and their caregivers, after controlling the variance explained by illness beliefs, coping responses and demographic variables?

## **Methods**

### ***Design***

This study used a cross-sectional survey design, using self-reported questionnaires to explore the relationships between coping responses, illness beliefs, self-compassion and psychological adjustment (in terms of anxiety, depression and QoL) in people experiencing the early stages of PD and their caregivers.

Through the support of Parkinson's UK Patient and Public Involvement, experts by experience reviewed the study design and research materials prior to ethical submission. Their feedback was used to adapt the protocol and materials as required.

## ***Ethics***

Ethical approval was granted by the National Health Service (NHS) Health Research Authority through the South West – Cornwall and Plymouth Research Ethics Committee, Reference Number 18/SW/0113 (See Appendix 5). NHS Research and Development approval was also granted by NHS Lothian as the study site. Participant identification centre (PIC) approval was granted by NHS Research and Development for NHS Tayside and NHS Lanarkshire (see Appendix 6).

## ***Eligibility of Participants***

Inclusion criteria for participants living with PD were as follows: (1) confirmed diagnosis of idiopathic PD at least 6 months prior to recruitment for the study; (2) identified by the referring health professional to present with mild PD; (3) meeting the criteria of stage 1 or 2 of the Hoehn and Yahr scale (Hoehn & Yahr, 1967); and (4) able to speak, read and write proficient English. Exclusion criteria for participants living with PD were as follows: (1) diagnosis of PD dementia and/or of mild cognitive impairment; (2) cognitive impairment which could negatively impact on their ability to provide informed consent and to understand and complete questionnaires; and (3) unwilling or unable to provide informed consent.

Inclusion criteria for caregivers were as follows: (1) consents to participation in the study, the caregiver normally lives with the care receiver; (2) the caregiver is directly responsible for their care receiver's care (for example they may provide physical and/or emotional support); and (3) over the age of 18 years. Exclusion criterion for caregivers was being a paid professional employed to care for the care receiver.

## ***Recruitment***

All potential participants were identified across NHS Lothian, NHS Lanarkshire and NHS Tayside between November 2018 to June 2019. Within these health boards, people with PD who met the study criteria, were provided with information about the study by clinicians. Clinicians supporting the study were experienced in working with people with PD i.e. Parkinson's Specialist Nurses, Neurologists and Specialist Physicians. Clinicians identified potential participants from their clinical case load. They initially discussed the study with their patients face-to-face or over the phone, prior to providing them with an information pack about the study (including a participant information sheet, consent form and stamped addressed envelope). Participants were recruited through the return of a completed consent form to the Chief Investigator (First Author), and in return a questionnaire pack was sent to the participant.

Participants living with PD indicated through their consent form whether they consented to their caregiver participating in the study, which resulted in a caregiver information pack (including a participant information sheet, consent form and stamped addressed envelope) being posted to the participant for their caregiver. Caregivers provided consent by returning the completed consent form to the Chief Investigator (First Author) resulting in them being sent a questionnaire pack.

Through the recruitment pathway outlined above, 71 completed consent forms were returned by participants living with PD and 67 questionnaires returned (94% return rate). Of the 71 consent forms returned by participants living with PD, 68% (n=48)

consented to a caregiver information pack being posted. 30 completed consent forms were returned by caregivers and 26 questionnaires returned (87% return rate).

### ***Materials***

The measures used are outlined below, which were completed by both participants living with PD and their caregivers unless otherwise stated.

#### *Demographic and Health Information*

A brief demographic and health information questionnaire was developed for participants living with PD to establish the following: age; gender; caregiver status; relationship status; employment; education; years since diagnosis of PD; comorbidity; medication; and socioeconomic status. The socioeconomic status was derived from the post codes provided by participants. Using the Scottish Index of Multiple Deprivation (SIMD) 2016, post codes were ranked by the SIMD decile rating, with 1 being the most deprived and 10 the least deprived (Scottish Government, 2016).

Caregiver demographic and characteristics were established through the caregiver QoL measure, the Adult Carer Quality of life Questionnaire (ACQoL), later outlined (Joseph, Becker, Elwick, & Silburn, 2012). The demographic information gathered included: age; gender; hours providing caregiving; and years being a caregiver.

#### *Coping Responses*

The Brief COPE is a 28-item self-report questionnaire which measures different coping responses (Carver, 1989). The Brief COPE has been used within research for

people living with PD and caregivers and has been shown to be a reliable and valid measure for caregivers and similar health populations (Navarta-Sánchez et al., 2016; Yusoff, Low, & Yip, 2010). The questionnaire is separated into the following 14 subscales of coping behaviours: denial; venting; behavioural disengagement; substance misuse; positive reframing; planning; acceptance; religion; self-blame; self-distraction; active coping; humour; use of emotional support; and use of instrumental support. In line with previous research, the total score provided was used for the analysis (Navarta-Sánchez et al., 2016). Analysis of each individual subscale was considered beyond the remit of this study. Cronbach's alpha for the total coping responses in this study for the sample of participants living with PD was .82, and .74 for caregivers.

### *Illness Beliefs*

The Brief-Illness Perception Questionnaire (Brief-IPQ) is a self-report questionnaire measuring a participant's belief about their illness (Broadbent, Petrie, Main, & Weinman, 2006). Research has demonstrated the Brief-IPQ has good validity and test-retest reliability (Broadbent et al., 2006). The Brief-IPQ statements are rated by participants on a Likert scale from 0-10, and each statement corresponds to the following dimensions; consequences, identity, treatment control, personal control, concerns, coherence, timeline and emotional representation (Broadbent et al., 2015). In line with similar research, the Brief-IPQ provided to caregivers adapted the phrase 'my illness' to 'your care receiver's illness' (Bassi et al., 2016). The subscale of 'emotional representation' was not included in analysis due to potential overlap with the psychological adjustment outcome measures. The subscale of 'causes' was also



not included within analysis due to previous research demonstrating this subscale to have poor validity and reliability (Moss-Morris et al., 2002; Simpson et al., 2013).

### *Self-Compassion*

The Self-Compassion Scale (SCS) is a 26-item self-report scale of self-compassion (Neff, 2003). Research has demonstrated the measure to have good internal validity and test-retest reliability (Neff, 2003; Neff & McGehee, 2010; Przewdziecki et al., 2013). The SCS covers 6 subscales (self-kindness, common humanity, self-judgement, over-identification, mindfulness and isolation), and provides a total score for self-compassion. Participants answer each question on a 5-point Likert scale from ‘almost never’ to ‘almost always’ in relation to how they act towards themselves during difficult times. Cronbach’s alpha for the total self-compassion score in this study for the sample of participants living with PD was .87, and .95 for caregivers.

### *Quality of Life*

Participants living with PD completed the Parkinson’s disease Questionnaire (PDQ-8) which measures QoL in people with PD (Peto, Jenkinson, Fitzpatrick, & Greenhall, 1995). The PDQ-8 is a shortened version of the Parkinson’s disease Questionnaire 39-item developed by Jenkinson, Fitzpatrick, Peto, Greenhall and Hyman (1997). Research has shown the PDQ-8 to be a valid and reliable measure of QoL (Tan, Lau, Au, & Luo, 2007). The PDQ-8 provides a total score, derived from eight subscales (activities of daily living, mobility, emotional wellbeing, stigma, cognitions, social support, communication, and bodily discomfort). Cronbach’s alpha for the total score in this study for the sample of participants living with PD was .80.

Caregivers completed the ACQoL, a 40-item self-report questionnaire assessing QoL in caregivers (Joseph et al., 2012). The ACQoL demonstrates excellent consistency reliability (Joseph et al., 2012; Brand et al., 2016), and shown to be a valid tool within caregivers of stroke survivors (Mei, Lin, Li, Ding & Zhang, 2017). The ACQoL assesses eight subscales (sense of value, support for caring, money matters, caring choice, caring stress, ability to care, personal growth and carer satisfaction), which cumulate into a total score. Cronbach's alpha for the total score in this study for the sample of caregivers was .94.

### *Psychological Distress*

The Hospital Anxiety and Depression Scale (HADS) is a validated measure with good test-retest reliability (Snaith & Zigmond, 1986). It has been used within similar research exploring distress in people living with PD, as well as caregivers of people experiencing chronic illnesses (Evans & Norman, 2009; Marinus, Leentjens, Visser, Stiggelbout, & van Hilten, 2002; Schellekens et al., 2017). The HADS is a 14-item self-report questionnaire, half the items assess anxiety and half the items measure depression, providing total scores for each of these domains. Cronbach's alpha for the total anxiety score in this study for the sample of participants living with PD was .85, and .82 for caregivers. Cronbach's alpha for the total depression score in this for the sample of participants living with PD was .87, and .81 for caregivers.

## *Statistical Analysis*

### *Power Analysis*

Research exploring illness representations and coping responses in people living with PD has found medium effect sizes (Evans & Norman, 2009; Navarta-Sánchez et al., 2016). Therefore, a priori calculation based on detecting a medium effect size, with a power of 0.8 and a significance of 0.05 was calculated using G\*Power. This resulted in sample size of 92 participants living with PD required for the planned analysis. Similar research with caregivers has also demonstrated medium effect sizes, with fewer predictors (Kaptein et al., 2007; Navarta-Sánchez et al., 2016), and as a result 77 was the sample size determined for caregivers.

### *Missing Data*

Participants who had more than 20% of items missing per questionnaire were removed from analysis. This resulted in 4 participants being removed (participants living with PD = 1; caregivers = 3). Little's Missing Completely at Random test was used to assess the pattern of missing values for the remaining participants across scales, results indicated data was missing at random. Analysis of missing data also found that less than 10% was missing per variable and therefore, the expectation-maximisation (EM) method was used to impute missing data.

### *Planned Analysis*

The IBM Statistical Package for Social Sciences (SPSS) version 23 was used for data analyses. Descriptive analysis was used to report demographic information and mean

scores on all variables. Prior to correlational analysis, the presence of outliers was assessed for all variables. Violation of normal distribution was assessed prior to caregiver analysis due to the small sample size (Field, 2018). Where normal distribution was not found, log transformations were conducted (Field, 2018). If data did not present as normally distributed following transformation, then non-parametric Spearman's correlation was undertaken.

To identify any associations between demographics and measures of psychological adjustment (depression, anxiety and QoL), preliminary correlational analysis was undertaken using Pearson correlations and independent sample t-tests. Correlational analysis was also conducted to assess associations between predictor variables and each dependent variable using Pearson correlations and Spearman's correlations. Variables found to be significantly associated with the dependent variable (depression, anxiety and QoL) were included within the hierarchical multiple regression models ( $p \leq 0.05$ ).

Hierarchical multiple regression was undertaken to assess for the additional variation accounted by illness beliefs, coping responses, and self-compassion for each of the psychological adjustment outcomes (depression, anxiety and QoL). Within each model, demographics found to be correlated with the outcomes were included firstly. In line with previous research, the more established predictors of illness beliefs were then added to the model, followed by coping responses if correlated, and finally self-compassion was added. The coping responses total score was added after illness beliefs due to the CSM theory proposing illness beliefs dictate coping responses (Leventhal

et al., 2016). Self-compassion was the last variable added to the model to assess its predictive power against more established predictors. Prior to running each regression model, analysis was undertaken to check for assumptions required (i.e. collinearity, independent errors, normally distributed standard errors and standard residuals, non-zero variances).

## **Results**

### ***Descriptive Statistics***

Completed consent forms and questionnaires were returned by 67 participants living with PD and 27 of their caregivers. Accounting for missing data, 66 participants living with PD and 24 caregivers were included in analysis. Demographic and clinical information gathered from participants are presented in Table 4 and Table 5.

Table 4. Demographic and Clinical Information of Participants living with PD

<b>Variable</b>	<b>Mean (SD) or number (%)</b>
Age	68.65 (8.17)
Gender	
Female	24 (36.4)
Years in education	14.47 (5.45)
Relationship status	
Single	5 (7.6)
Married or cohabitating	47 (71.2)
Separated or divorced	7 (10.6)
Widowed	7 (10.6)
Caregiver status	
No caregiver	24 (36.9)
Spouse is caregiver	38 (58.5)
Child is caregiver	1 (1.5)
Caregiver other	2 (3.1)
Employment status	
Working (full or part time)	5 (7.6)
Not working (retired or unemployed)	61 (92.4)
Socio-economic status	
Deciles 1-3	9 (13.6)
Deciles 4-7	26 (39.4)
Deciles 8-10	31 (47.0)
Years since diagnosis of PD	4.55 (3.97)
Comorbidity of other long-term health condition	59 (39)
Receiving dopaminergic medication	60 (91)

Table 5. Demographic Information of Caregivers

<b>Variable</b>	<b>Mean (SD) or number (%)</b>
Age	67.42 (7.22)
Gender	
Female	14 (58.3)
Years being a Caregiver	3.71 (2.54)
Relationship to Care Receiver	
Spouse	21 (87.5)
Other	3 (12.5)
Caregiving hours per week	
≤10	12 (52.2)
11-50	5 (21.7)
≥51	6 (26.1)

Table 6. Means for Participants living with PD and Caregivers

Variables	Participants living with PD (n=66)			Caregivers (n=24)		
	Mean (SD)	Ranges Min Max		Mean (SD)	Ranges Min Max	
IPQ Consequences	6.03 (2.61)	1	10	5.42 (2.78)	1	10
IPQ Timeline	9.68 (.79)	6	10	9.46 (1.22)	5	10
IPQ Personal control	4.42 (2.57)	0	10	2.75 (2.44)	0	9
IPQ Treatment control	6.73 (2.35)	0	10	6.75 (2.03)	2	10
IPQ Identity	5.74 (2.40)	1	10	3.38 (2.90)	0	8
IPQ Illness concern	7.18 (2.52)	1	10	8.08 (2.30)	2	10
IPQ Illness coherence	6.70 (2.41)	0	10	7.48 (1.78)	4	10
Brief COPE Total	55.47 (10.12)	34	82	48.71 (8.30)	36	68
SCS Total	84.67 (14.62)	53	124	85.29 (18.91)	40	116
HADS Anxiety	7.23 (4.17)	0	18	6.25 (3.50)	0	13
HADS Depression	6.41 (3.96)	0	18	4.08 (3.11)	0	10
PDQ-8	32.67 (18.28)	3.13	75.00	-	-	-
ACQoL	-	-	-	76.25 (18.93)	28	107

IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale, HADS = Hospital Anxiety and Depression Scale, PDQ-8 = Parkinson's disease Questionnaire 8-item total score  
ACQoL = Adult Carer Quality of Life Questionnaire total score

Means and standard deviations for predictors and outcome variables are presented in Table 6. Mean scores for anxiety were 7.23 (SD=4.17) for participants living with PD and 6.25 (SD=3.50) for caregivers. Means scores for depression for participants living with PD were 6.41 (SD=3.96) and 4.08 (SD=3.11) for caregivers. Scores  $\geq 8$  for each subscale of the HADS are recommended clinical cut-offs (Snaith & Zigmond, 1986). Whereas, scores  $\geq 10$  are the recommended clinical cut-offs for people living with PD on each subscale (Schrag et al., 2007; Leentjens et al., 2011). Therefore, 30% (n=22) of participants living with PD and 33% (n=8) of caregivers were within the clinical range for anxiety. Whilst 20% (n=13) of participants living with PD and 17% (n=4) were within the clinical range for depression. The mean QoL score for participants

living with PD was 32.67 (SD=18.28), with higher scores on the PDQ-8 indicating poorer QoL (max. score = 100). The mean QoL score for caregivers was 76.25 (SD=18.93), with higher scores on the ACQoL indicating greater QoL (max. score = 120).

### ***Control Variables***

Analysis was undertaken to establish demographic variables associated to dependent variables, to ascertain a need for their control in regression analysis. Pearson correlations for participants living with PD indicated there was a positive association between years since diagnosis and depression ( $r(66) = .25, p = .042$ ), and a negative association between years since diagnosis and QoL ( $r(66) = .31, p = .011$ ). Pearson correlations for caregivers indicated age was positively associated with QoL ( $r(24) = .46, p = .024$ ). Years as a caregiver was positively associated with anxiety ( $r(24) = .67, p < 0.001$ ) and depression ( $r(24) = .53, p = .009$ ). Whereas, years as a caregiver was negatively associated with QoL ( $r(24) = -.61, p = .002$ ). As a result, these identified demographic and clinical predictors were included within the hierarchical multiple regression model when required.

### ***Correlation Analysis***

Correlation analysis was undertaken for predictor variables in both participants with PD and caregivers (see Table 7 and Table 8 respectively). Only variables which were found to be statistically associated with an outcome of psychological adjustment were included for further analysis within the hierarchical multiple regression models specific to that outcome ( $p \leq 0.05$ ). The regression models also included the



demographic variables previously outlined as being significantly associated with the outcomes of psychological adjustment.

Table 7. Correlation Analysis for Participants living with PD (N=66)

	Anxiety <i>r</i> (p)	Depression <i>r</i> (p)	QoL <i>r</i> (p)
Years since PD diagnosis	.029 (.819)	.251* (.042)	.311* (.011)
IPQ Consequences	.527** (.000)	.599** (.000)	.698** (.000)
IPQ Timeline	.168 (.179)	.136 (.276)	-.019 (.883)
IPQ Personal Control	-.400** (.001)	-.473** (.000)	-.463** (.000)
IPQ Treatment Control	-.292* (.017)	-.218 (.079)	-.261* (.035)
IPQ Identity	.501** (.000)	.532** (.000)	.734** (.000)
IPQ Illness Concern	.518** (.000)	.290* (.018)	.444** (.000)
IPQ Illness Coherence	-.143 (.252)	-.037 (.766)	-.018 (.883)
Brief COPE Total	.341** (.005)	-.058 (.642)	.212 (.088)
SCS Total	-.454** (.000)	-.458** (.000)	-.433** (.000)

\*0.05 (two-tailed); \*\*0.01 (two-tailed), IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale

Table 8. Correlation Analysis for Caregivers (N=24)

	Anxiety <i>r</i> (p)	Depression <i>r</i> (p)	QoL <i>r</i> (p)
Age	-.229 (.281)	-.089 (.679)	.458* (.024)
Years as caregiver <sup>1</sup>	.672** (.000)	.525** (.009)	-.608** (.002)
IPQ Consequences	.721* (.000)	.540* (.007)	.629** (.001)
IPQ Timeline <sup>2</sup>	-.010 (.964)	-.060 (.779)	-.230 (.280)
IPQ Personal Control	-.497* (.014)	-.359 (.085)	-.574** (.003)
IPQ Treatment Control	-.419* (.041)	-.280 (.186)	.419* (.042)
IPQ Identity	.495* (.014)	.431 (.036)	-.473* (.020)
IPQ Illness Concern <sup>1</sup>	-.247 (.244)	-.201 (.347)	.167 (.437)
IPQ Illness Coherence	-.233 (.274)	-.047 (.828)	-.016 (.942)
Brief COPE Total	.302 (.152)	.284 (.178)	-.329 (.116)
SCS	-.714** (.000)	-.529** (.008)	.826** (.000)

<sup>1</sup>transformed (log); <sup>2</sup>Spearman rho; \*0.05 (two-tailed); \*\*0.01 (two-tailed), IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale

### ***Hierarchical Multiple Regression Analysis***

Assumptions required for multiple regressions were assessed, all of which were met (i.e. collinearity, independent errors, normally distributed errors and standard residuals, and non-zero variances). Therefore, hierarchical multiple regression was conducted, using a model for each dependent variable (anxiety, depression and QoL).

#### ***Predictors for Participants living with PD***

To understand predictor variables for anxiety in participants living with PD, hierarchical regression was conducted using three steps (see Table 9). In the first step, illness beliefs (consequences, personal control, treatment control, identity, and illness concern) were included, which accounted for 32.6% of variance in anxiety scores ( $R^2 = .378$ , adjusted  $R^2 = .326$ ,  $p < .001$ ). The second step added coping responses, accounting for an additional variance of 2.4% ( $R^2 = .401$ , adjusted  $R^2 = .340$ ,  $R^2$  change = .024,  $p = .132$ ). The final step added self-compassion, accounting for an additional variance of 5.3% ( $R^2 = .454$ , adjusted  $R^2 = .389$ ,  $R^2$  change = .053,  $p = .021$ ). Regression co-efficients exposed both total coping responses and self-compassion as significant independent predictor of total variance. Greater coping response was associated with more symptoms of anxiety ( $\beta = .098$ ,  $t = 2.161$ ,  $p = .035$ ), and lower levels of self-compassion were predictive of more symptoms of anxiety ( $\beta = -.080$ ,  $t = -2.378$ ,  $p = .021$ ). Total variance accounted for by this model was 38.9%,  $F(7,58) = 6.903$ ,  $p < .001$ .

Hierarchical regression using three steps was conducted to understand predictor variables for depression in participants living with PD (see Table 10). The first step included years since PD diagnosis which accounted for 4.8% of variance in symptoms

of depression ( $R^2 = .063$ , adjusted  $R^2 = .048$ ,  $p = .042$ ). The second step added illness beliefs (consequences, personal control, identity, and illness concern) which accounted for an additional variance of 34.7% ( $R^2 = .410$ , adjusted  $R^2 = .360$ ,  $R^2$  change = .347,  $p < .001$ ). The final step added self-compassion, which accounted for an additional variance of 4.5% ( $R^2 = .455$ , adjusted  $R^2 = .399$ ,  $R^2$  change = .045,  $p = .031$ ). Regression co-efficient revealed the ‘consequences’ and self-compassion were independent variables of total variance of depression symptoms. With belief in more severe consequences of PD associated with greater levels of depressive symptoms ( $\beta = .674$ ,  $t = 2.437$ ,  $p = .018$ ), and lower levels of self-compassion predictive of more severe symptoms of depression ( $\beta = -.067$ ,  $t = -2.208$ ,  $p = .031$ ). The total variance accounted for by this model was 39.9%,  $F(6,59) = 8.198$ ,  $p < .001$ .

Hierarchical regression using three steps was conducted to understand predictor variables for QoL in participants living with PD (see Table 11). The first step included years since diagnosis of PD, which accounted for 8.3% of variance in QoL ( $R^2 = .097$ , adjusted  $R^2 = .083$ ,  $p = .011$ ). The second step added illness beliefs (consequences, personal control, treatment control, identity, and illness concern), which resulted in an additional 48.7% variance ( $R^2 = .584$ , adjusted  $R^2 = .542$ ,  $R^2$  change = .487,  $p < .001$ ). The final step added self-compassion which accounted for an additional 0.7% variance ( $R^2 = .591$ , adjusted  $R^2 = .542$ ,  $R^2$  change = .007,  $p = .311$ ). The illness belief of ‘identity’ was found through regression co-efficient to be an independent predictor of variance in QoL, with stronger illness identity associated with poorer QoL ( $\beta = 3.324$ ,  $t = 2.848$ ,  $p = .006$ ). The total variance accounted for by this model was 54.2%,  $F(7,58) = 11.988$ ,  $p < .001$ .

Table 9. Hierarchical regression to predict anxiety in participants living with PD

Variable	B	Lower	Upper	B Standardised	T	p-value	R	R <sup>2</sup>	ΔR <sup>2</sup>	F for R <sup>2</sup> change
Step 1							.614	.378	.326	7.280**
IPQ Consequences	.330	-.270	.929	.206	1.099	.276				
IPQ Personal Control	-.087	-.537	.364	-.053	-.384	.702				
IPQ Treatment Control	-.235	-.663	.192	-.133	-1.100	.276				
IPQ Identity	.204	-.429	.837	.118	.645	.521				
IPQ Illness Concern	.478	-.059	.897	.289	2.282	.026*				
Step 2							.633	.401	.340	2.339
IPQ Consequences	.295	-.300	.890	.185	.993	.325				
IPQ Personal Control	-.163	-.620	.294	-.100	-.714	.478				
IPQ Treatment Control	-.192	-.619	.235	-.108	-.900	.372				
IPQ Identity	.159	-.470	.787	.091	.505	.615				
IPQ Illness Concern	.411	-.013	.835	.249	1.940	.057				
Brief COPE Total	.069	-.021	.160	.168	1.529	.132				
Step 3							.674	.454	.389	5.655*
IPQ Consequences	.299	-.274	.873	.187	1.046	.300				
IPQ Personal Control	-.096	-.540	.347	-.059	-.435	.665				
IPQ Treatment Control	-.200	-.611	.212	-.113	-.972	.335				
IPQ Identity	.005	-.614	.624	.003	.017	.986				
IPQ Illness Concern	.284	-.138	.706	.172	1.349	.183				
Brief COPE Total	.098	-.007	.189	.238	2.161	.035*				
SCS Self-compassion	-.080	-.147	-.013	-.281	-2.378	.021*				

\*p < 0.05, IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale

Table 10. Hierarchical regression to predict depression in participants living with PD

Variable	B	Lower	Upper	B Standardised	T	p-value	R	R <sup>2</sup>	ΔR <sup>2</sup>	F for R <sup>2</sup> change
Step 1							.251	.063	.048	4.293*
Duration of PD	.250	.009	.491	.251	2.072	.042*				
Step 2							.640	.410	.360	8.810**
Duration of PD	.066	-.151	.283	.066	.608	.545				
IPQ Consequences	.653	.082	1.223	.430	2.288	.026*				
IPQ Personal Control	-.358	-.723	.007	-.232	-1.960	.055				
IPQ Identity	.178	-.415	.760	.105	.587	.559				
IPQ Illness Concern	-.160	-.560	.240	-.102	.802	.426				
Step 3							.674	.455	.399	4.874*
Duration of PD	.055	-.155	.266	.056	.527	.600				
IPQ Consequences	.674	.121	1.228	.444	2.437	.018*				
IPQ Personal Control	-.285	-.645	.076	-.184	-1.580	.119				
IPQ Identity	.060	-.519	.639	.036	.208	.836				
IPQ Illness Concern	-.248	-.644	.148	-.158	-1.254	.215				
SCS Self-compassion	-.067	-.129	-.006	-.249	-2.208	.031*				

\*p < 0.05, IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale

Table 11. Hierarchical regression to predict QoL in participants living with PD

Variable	B	Lower	Upper	B standardised	T	p-value	R	R <sup>2</sup>	ΔR <sup>2</sup>	F for R <sup>2</sup> change
Step 1							.311	.097	.083	6.859*
Duration of PD	1.433	.340	2.526	.311	2.619	.011*				
Step 2							.764	.584	.542	13.817**
Duration of PD	.444	-.412	1.301	.096	1.038	.303				
IPQ Consequences	1.563	-.699	3.794	.223	1.401	.166				
IPQ Personal Control	-.556	-2.204	1.092	-.078	-.675	.502				
IPQ Treatment Control	-.389	-1.952	1.175	-.050	-.497	.621				
IPQ Identity	3.530	1.229	5.831	.464	3.070	.003**				
IPQ Illness Concern	.149	-1.415	1.714	.021	.191	.849				
Step 3							.769	.591	.542	1.043
Duration of PD	.421	-.437	1.279	.091	.983	.330				
IPQ Consequences	1.605	-.627	3.838	.229	1.439	.155				
IPQ Personal Control	-.395	-2.073	1.283	-.055	-.471	.639				
IPQ Treatment Control	-.435	-2.001	1.131	-.056	-.556	.581				
IPQ Identity	3.324	.988	5.660	.437	2.848	.006**				
IPQ Illness Concern	-.017	-1.615	1.581	-.002	-.021	.983				
SCS Self-compassion	-.126	-.373	.121	-.101	-1.021	.311				

\*p < 0.05; \*\*p < 0.01, IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale

Table 12. Hierarchical regression to predict anxiety in caregivers

Variable	B	Lower	Upper	B standardised	T	p-value	R	R <sup>2</sup>	ΔR <sup>2</sup>	F for R <sup>2</sup> change
Step 1							.706	.498	.475	21.817**
Years as Caregiver	.972	.540	1.403	.706	4.671	.000**				
Step 2							.841	.706	.625	3.197*
Years as Caregiver	.384	-.174	.941	.279	1.446	.165				
IPQ Consequences	.477	-.058	1.011	.378	1.872	.078				
IPQ Personal Control	-.296	-.732	.141	-.206	-1.424	.171				
IPQ Treatment Control	-.382	-.895	.130	-.221	-1.566	.135				
IPQ Identity	.104	-.301	.508	.086	.540	.596				
Step 3							.849	.720	.622	.814
Years as Caregiver	.304	-.288	.896	.221	1.083	.294				
IPQ Consequences	.418	-.138	.974	.332	1.588	.131				
IPQ Personal Control	-.223	-.694	.248	-.155	-.999	.332				
IPQ Treatment Control	-.343	-.868	.181	-.199	-1.380	.185				
IPQ Identity	.085	-.325	.495	.070	.463	.668				
SCS Self-compassion	-.034	-.112	.044	-.183	-.917	.372				

\*\* p < 0.01, IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale

Table 13. Hierarchical regression to predict depression in caregivers

Variable	B	Lower	Upper	B Standardised	T	p-value	R	R <sup>2</sup>	ΔR <sup>2</sup>	F for R <sup>2</sup> change
Step 1							.592	.350	.321	11.860**
Years as Caregiver	.722	.287	1.157	.592	3.444	.002**				
Step 2							.612	.375	.315	.025*
Years as Caregiver	.517	-.124	1.159	.424	1.678	.108				
IPQ Consequences	.257	-.330	.844	.230	.910	.373				
Step 3							.630	.397	.307	.732
Years as Caregiver	.414	-.280	1.109	.340	1.245	.227				
IPQ Consequences	.181	-.440	.802	.162	.608	.550				
SCS Self-compassion	-.034	-.116	.048	-.205	-.856	.402				

\*  $p < 0.05$ , \*\*  $p < 0.01$ , IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale



Table 14. Hierarchical regression to predict QoL in caregivers

Variable	B	Lower	Upper	B standardised	T	p-value	R	R <sup>2</sup>	ΔR <sup>2</sup>	F for R <sup>2</sup> change
Step 1							.785	.616	.580	16.849**
Age	1.109	.371	1.848	.423	3.123	.005**				
Years as Caregiver	-4.751	-6.846	-2.656	-.639	-4.716	.000**				
Step 2							.861	.742	.651	2.078
Age	.913	.070	1.755	.348	2.284	.036*				
Years as Caregiver	-2.377	-5.296	.541	-.320	-1.719	.104				
IPQ Consequences	-2.115	-4.986	.755	-.311	-1.555	.138				
IPQ Personal Control	.960	-1.761	3.680	.123	.744	.467				
IPQ Treatment Control	2.103	-.602	4.808	.225	1.641	.119				
IPQ Identity	-.153	-2.360	2.054	-.023	-.146	.886				
Step 3							.885	.784	.689	3.063
Age	.505	-.435	1.444	.192	1.139	.271				
Years as Caregiver	-1.463	-4.445	1.519	-.197	-1.040	.314				
IPQ Consequences	-1.168	-4.123	1.787	-.172	-.838	.414				
IPQ Personal Control	.875	-1.709	3.458	.113	.718	.483				
IPQ Treatment Control	1.508	-1.157	4.174	.161	1.199	.248				
IPQ Identity	-.246	-2.343	1.851	-.038	-.249	.807				
SCS Self-compassion	.378	-.079	.823	.372	1.750	.099				

\*p < 0.05, \*\*p < 0.01, IPQ = Brief Illness Perception Questionnaire illness belief, SCS = Self-Compassion Scale

### *Predictors for Caregivers*

To understand predictor variables for anxiety in caregivers, hierarchical regression using three steps was conducted (see Table 12). In the first step, years as a caregiver was included, accounting 47.5% of variance in anxiety scores ( $R^2 = .498$ , adjusted  $R^2 = .475$ ,  $p < .001$ ). The second step included illness beliefs (consequences, personal control, treatment control, and identity) for analysis, which resulted in an additional variance of 20.9% ( $R^2 = .706$ , adjusted  $R^2 = .625$ ,  $R^2$  change = .209,  $p = .038$ ). The final step added in self-compassion, which accounted for an additional 1.4% of variance ( $R^2 = .720$ , adjusted  $R^2 = .622$ ,  $R^2$  change = .014,  $p = .372$ ). Regression co-efficients revealed no independent predictors variables for total variance of anxiety symptoms. The total variance accounted for by this model was 62.2%,  $F(6,17) = 7.297$ ,  $p = .001$ .

Hierarchical regression using three steps was conducted to understand predictor variables for depression in caregivers (see Table 13). Within the hierarchical regression model exploring depression, the first step included years as a caregiver, which accounted for variance of 32.1% ( $R^2 = .359$ , adjusted  $R^2 = .321$ ,  $R^2$  change = .350,  $p = .002$ ). The second step added illness beliefs (consequence) for analysis, which accounted for variance of 2.5% ( $R^2 = .375$ , adjusted  $R^2 = .315$ ,  $R^2$  change = .025,  $p = .373$ ). The final step added in self-compassion, which accounted for an additional 2.2% of variance ( $R^2 = .397$ , adjusted  $R^2 = .307$ ,  $R^2$  change = .022,  $p = .402$ ). Regression co-efficient analysis highlighted no independent predictors of variance for depression. The total variance accounted for by this model was 30.7%,  $F(3,20) = 4.389$ ,  $p = .016$ .

Hierarchical regression using three steps was conducted to understand predictor variables for QoL in caregivers (see Table 14). The model firstly included age and years since as caregiver, which accounted for 58% of variance in QoL ( $R^2 = .616$ , adjusted  $R^2 = .580$ ,  $p < .001$ ). The second step added illness beliefs (consequences, personal control, treatment control, identity) which resulted in additional 12.6% of variance ( $R^2 = .742$ , adjusted  $R^2 = .651$ ,  $R^2$  change = .126,  $p = .129$ ). The final step added self-compassion resulting in an additional 4.1% variance ( $R^2 = .784$ , adjusted  $R^2 = .689$ ,  $R^2$  change = .041,  $p = .099$ ). Regression co-efficient analysis highlighted no independent predictors of variance for QoL. The total variance accounted for by this model was 68.9%,  $F(7,16) = 8.276$ ,  $p < .001$ .

## **Discussion**

This study aimed to explore whether illness beliefs and coping responses have an association with psychological adjustment (in terms of depression, anxiety and QoL) in people living with PD and their caregivers. In addition, this study aimed to explore the role of self-compassion in psychological adjustment for people living with PD and caregivers.

Results indicated illness beliefs accounted for significant variance in anxiety for both participants living with PD and caregivers, as well as depression and QoL for participants living with PD. The only illness beliefs found to be independent predictors were ‘consequences’ and illness ‘identity’ in participants living with PD. With participants living with PD who perceive their illness to have more significant consequences, experiencing more severe symptoms of depression. Whereas, those who hold a stronger illness ‘identity’ experience poorer QoL. The results from the

participants living with PD are consistent with Evans and Norman (2009) who found illness beliefs to explain significant variance in depression and anxiety scores, alongside the illness belief of ‘consequences’ being an independent predictor of depression symptoms. Similarly, the illness belief of ‘identity’ being associated with QoL is also in line with previous research (Hurt et al., 2014).

The findings of this study, alongside previous research (Evans & Norman, 2009; Hurt et al., 2014), indicate that some of the core illness beliefs outlined by the CSM may not be of relevance for those affected by PD. Equally, this research could indicate a minority of key illness beliefs are of more importance in the early stages of PD. The CSM describes a dynamic process with illness beliefs being continually appraised, therefore, future longitudinal research could identify if other core illness beliefs are of more importance in psychological adjustment as PD progresses.

This study also found greater coping responses only accounted for additional variance in relation to anxiety of participants living with PD, differing from previous research demonstrating greater coping responses predict better psychological adjustment (Navarta-Sánchez et al., 2016). The findings of this study may contrast with those of Navarta-Sanchez et al. (2016), due to their lack of controlling for additional and more established predictors when analysing the association between coping responses and psychological adjustment. Research in people living with PD indicate anxiety is associated with maladaptive coping strategies, such as avoidance and resignation (Evans & Norman, 2009). Therefore, the association between anxiety and greater coping responses, may be due to participants in this study engaging in a greater number

of maladaptive coping responses. This highlights that more importance should be placed on each coping responses' success at reducing psychological distress, rather than on the extent to which people are engaging in coping strategies.

Self-compassion was found as an independent predictor for symptoms of anxiety and depression in people living with PD. The findings support previous research which found better psychological wellbeing in those with more self-compassion (Wren et al., 2012; Pinto-Gouveia et al., 2013; Schellekens et al., 2017). It is theorised that self-compassion regulates negative emotions (Finlay-Jones, 2017). This may account for participants living with PD with greater self-compassion experiencing less symptoms of anxiety and depression.

The complexity of the construct of QoL may account for the lack of association between self-compassion and QoL. Research indicates that QoL for people living with PD are influenced by a wide range of interacting factors unique to each person (Dauwerse et al., 2014). It is possible that there could be a subgroup of people living with PD whose perceived QoL may be associated with self-compassion. To identify whether this is the case, qualitative research may be well placed to take into consideration the broad factors which contribute to QoL (e.g. relationship quality, communication, and culture), and their relationship with self-compassion.

This study also explored the role of self-compassion in caregivers, albeit finding no association. The scores on measures of psychological adjustment were low for caregivers, which could impact on the sensitivity to detect their associations with self-

compassion. This might partly be due to recruiting people within the mild stages of PD, where less day-to-day support may be required resulting in lower levels of distress for caregivers. Future research would require recruiting caregivers of people experiencing different severities of the condition to ascertain whether self-compassion may be of benefit as the demands of caregivers increase. A recent qualitative study by Vatter et al. (2018), exploring female caregivers experiences of supporting their spouses living with PD, found that as cognitive impairment declined and dementia began to emerge. The authors also found greater time was spent caregiving alongside the caregiver's marital satisfaction declining significantly (Vatter et al., 2018). As a result, future research which explores psychological adjustment across the PD needs to account for additional factors associated with psychological outcomes e.g. nature of relationship and quality of relationship.

Further consideration of the mutual benefits of self-compassion within psychological adjustment is also required. For example, research in other health conditions found that high self-compassion of a spouse may compensate for their partners low self-compassion, resulting in decreased distress for both (Schelleken et al., 2017). Previous studies have disregarded the benefits of including caregiver outcomes alongside people living with PD, preventing dyadic exploration of data (Evans & Norman, 2009; Hurt et al., 2014; Simpson et al., 2013). This study did consider the importance of caregivers in the adjustment of living with PD, yet, it was not possible to explore dyadic interactions due to the limited sample size. Future research should include caregivers to allow for individual and dyadic analysis to identify which factors improve caregiver outcomes as well as their care receivers.

### ***Strengths and Limitations of Study***

To the authors knowledge, this study is the first to explore the role of self-compassion in the adjustment to PD, for both people living with PD and their caregivers. This study also adds to the understanding of the role of illness beliefs and coping within the process of psychological adjustment. However, results need to be considered within the limitations of this study. Firstly, the cross-sectional design, although feasible within the limited timeframe and resources available, does not allow for conclusions to be drawn between the relationship of predictors and outcomes of psychological adjustment.

Another limitation of the study was the sample size recruited. The number of participants living with PD recruited was similar to previous research (Evans & Norman, 2009), yet there were difficulties recruiting the calculated sample size, especially for caregivers. It was noted that 68% (n=48) of participants living with PD consented for a caregiver to participate, limiting the pool of caregivers to recruit from. As a result, it was not possible to reach a sample size large enough to reduce the risk of type I and type II errors occurring.

The limited number of caregivers identified and recruited may be due to people within the early stages of PD not identifying themselves as receiving emotional and/or physical support from those close to them, due to less severe symptoms. A lack of consistent reporting of PD severity within the NHS regional boards meant the inclusion of severity as a predictor within the analysis was not feasible. This was considered as previous research has demonstrated that severity of PD is associated with QoL (Soh et

al., 2012; Hurt et al., 2014; Navarta-Sánchez et al., 2016). To allow for the greatest sample, this study recruited only people experiencing mild PD, as similar research found those who chose to participate predominantly presented with mild PD (Navarta-Sánchez et al., 2016). Consequently, excluding participants living with moderate to severe PD may have contributed to difficulties reaching the planned sample sizes, whilst limiting the ability to generalise findings to participants living with greater severity of PD and their caregivers.

### ***Clinical Implications***

This study found that illness beliefs may account for variation in psychological adjustment in both people living with PD and their caregivers. However, there appears to be variance in which illness belief may indicate better psychological adjustment. Therefore, a formulation-based approach may be the best way for health professionals to ascertain whether certain illness beliefs are contributing to poor adjustment within both people living with PD and their caregivers. Within this approach, exploring patient's identity in relation to their illness, alongside their perception of the consequences of their condition, is of importance due to their association with psychological distress. Due to the chronic nature of PD, unsurprisingly there may be a perception of severe consequences and attribution of their symptoms to their condition. Therefore, it is important that services can provide education about PD in the early stages of the condition. This study also highlights that some people living with mild PD may be struggling to adjust to their diagnosis and could benefit from specialised psychological input to help manage their distress.



As this study suggests both illness beliefs and self-compassion contribute to psychological distress in people living with mild PD, psychosocial interventions which address these factors may be beneficial for this population. CBT may be able to address illness beliefs which are contributing to poor psychological adjustment through cognitive restructuring. CBT also has growing evidence for its effectiveness in reducing anxiety and depression in people living with PD (Yang et al., 2012). However, CBT does not aim to address self-compassion, which this study has also shown to be associated with psychological distress.

Interventions which address self-compassion should be considered for those who may not have benefited from more established approaches for psychological distress e.g. pharmacology and CBT. One such intervention demonstrated to increase self-compassion is CFT (Leaviss & Uttley, 2015). Gilbert (2009) conceptualised CFT within a framework of the evolution of affect regulation systems. These systems have evolved in order to keep mammals safe and seek resources (Gilbert, 2014). CFT focuses on three systems; the ‘threat’ system recognises and responds to threats, the ‘drive’ system provides information to motivate resource seeking, and the ‘soothing’ system provides information on safety to activate rest and contentment (Gilbert, 2009). CFT aims to address imbalances within these systems, helping individuals initiate their ‘soothing’ system through self-compassion to respond to threats (with the ‘threat’ system associated with emotions such as anxiety and anger) (Leaviss & Uttley, 2015). It could be proposed that people living with PD may be vulnerable to difficulties in both ‘drive’ and ‘threat’ systems. Alongside the common symptom of anxiety associated with the ‘threat’ system, people living with PD commonly experience

apathy, potentially indicating deficits in the ‘drive’ system due to the depletion of dopamine (Muhammed et al., 2016). Further exploration of the interaction between apathy, psychological distress and self-compassion may help identify whether CFT can provide a unique approach to tackle imbalances of affect regulation systems in people living with PD. In the meantime, CFT should be considered for people living with PD who are experiencing significant psychological distress.

Within the wider context, the Scottish Government is in the process of approving the ‘5-year National Action Plan on Neurological Conditions’, aimed to provide the best care and support for both people living with neurological conditions and their caregivers (Scottish Government, 2018). This will offer the opportunity for those affected by PD, public services and the third sector to develop innovative approaches for better care. This research highlights that people living with mild PD and their caregivers may experience significant levels of psychological distress. Therefore, approaches which meet the psychological needs of this population should be a key consideration in future service development.

### ***Conclusions***

This study provides further evidence for the relationship between illness beliefs and psychological adjustment outcomes in people living with PD, whilst providing preliminary evidence of a relationship between outcomes of psychological adjustment (depression and anxiety) and self-compassion. However, due to the nature of the design of the study and limited sample size, conclusions cannot be drawn. Future studies with greater sample sizes utilising a longitudinal design are required to better

understand how self-compassion, coping strategies and illness beliefs may benefit people living with PD and their caregivers over the course of the condition.

### ***Declaration of Interests***

Authors declare that they have no potential conflict of interest.

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## **Appendices**

**Appendix 1: Clinical Rehabilitation Author Guidelines**

**Appendix 2: Studies excluded due to duplication of Participant Data**

**Appendix 3: Quality Appraisal Tools and Scoring**

**Appendix 4. Psychology & Health Author Guidelines**

**Appendix 5. Research Ethics Committee Approval**

**Appendix 6. Research & Development Approval**

**Appendix 7. Protocol**

**Appendix 8. Participant Information Sheet – Participant with PD**

**Appendix 9. Participant Information Sheet – Caregiver**

**Appendix 10. Consent Form – Participant with PD**

**Appendix 11. Consent Form – Caregiver**

**Appendix 12. Thesis Portfolio References**

## ***Appendix 1. Clinical Rehabilitation Author Guidelines***

*The following outlines the author guidelines, quoted and accessed from; <https://uk.sagepub.com/en-gb/eur/clinical-rehabilitation/journal201806#submission-guidelines>*

“This Journal is a member of the Committee on Publication Ethics

This Journal recommends that authors follow the Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals formulated by the International Committee of Medical Journal Editors (ICMJE).

**Please read the guidelines below then visit the Journal’s submission site <http://mc.manuscriptcentral.com/clinrehab> to upload your manuscript. Please note that manuscripts not conforming to these guidelines may be returned.**

Only manuscripts of sufficient quality that meet the aims and scope of Clinical Rehabilitation will be reviewed.

There are no fees payable to submit or publish in this journal.

As part of the submission process you will be required to warrant that you are submitting your original work, that you have the rights in the work, that you are submitting the work for first publication in the Journal and that it is not being considered for publication elsewhere and has not already been published elsewhere, and that you have obtained and can supply all necessary permissions for the reproduction of any copyright works not owned by you.

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## 1. What do we publish?

### 1.1 Aims & Scope

Before submitting your manuscript to Clinical Rehabilitation, please ensure you have read the [Aims & Scope](#).

### 1.2 Article Types

The journal publishes original papers, systematic reviews, Rehabilitation in Practice articles correspondence relating to published papers and short reports. Other article types should be discussed with the editor before submission.

For queries regarding the suitability of your submission please contact [clinical.rehabilitation@sagepub.co.uk](mailto:clinical.rehabilitation@sagepub.co.uk)

#### 1.2.1 Summary of manuscript structure:

- A title page with names and contact details for all authors;
- A **structured** abstract of **no more than 250 words** (the website checks this);
- The text (usually Introduction, Methods, Results, Discussion);
- Clinical Messages (2-4 bullet points, 50 words or less);
- Acknowledgements, author contributions, competing interests and funding support;
- References (Vancouver style);
- Tables, each starting on a new page;
- Figures, each starting on a new page;
- Appendix (if any).

Please note that short reports follow a different format:

- The main text of a short report will usually be between **1000 and 1500 words** in length.
- A short report should have sufficient key references to cover all important points, but no more and usually there will be a **maximum of 15 references**.
- Tables and figures can be very efficient and effective ways of presenting data. A short report will usually have **no more than three tables and figures** (in total) and most will be restricted to two.

Further information on short reports can be found [here](#).

### 1.3 Writing your paper

The SAGE Author Gateway has some general advice and on [how to get published](#), plus links to further resources.

### ***1.3.1 Make your article discoverable***

When writing up your paper, think about how you can make it discoverable. The title, keywords and abstract are key to ensuring readers find your article through search engines such as Google. For information and guidance on how best to title your article, write your abstract and select your keywords, have a look at this page on the Gateway: [How to Help Readers Find Your Article Online](#).

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## **2. Editorial policies**

### **2.1 Peer review policy**

The journal's policy is to obtain at least two independent reviews of each article. It operates a single-blind reviewing policy in which the reviewer's name is always concealed from the submitting author. Referees will be encouraged to provide substantive, constructive reviews that provide suggestions for improving the work and distinguish between mandatory and non-mandatory recommendations.

All manuscripts accepted for publication are subject to editing for presentation, style and grammar. Any major redrafting is agreed with the author but the Editor's decision on the text is final.

*Clinical Rehabilitation* is committed to delivering high quality, fast peer-review for your paper, and as such has partnered with Publons. Publons is a third party service that seeks to track, verify and give credit for peer review. Reviewers for *Clinical Rehabilitation* can opt in to Publons in order to claim their reviews or have them automatically verified and added to their reviewer profile. Reviewers claiming credit for their review will be associated with the relevant journal, but the article name, reviewer's decision and the content of their review is not published on the site. For more information visit the Publons website.

### **2.2 Authorship**

Papers should only be submitted for consideration once consent is given by all contributing authors. Those submitting papers should carefully check that all those whose work contributed to the paper are acknowledged as contributing authors.

The list of authors should include all those who can legitimately claim authorship. This is all those who:

- Made a substantial contribution to the concept or design of the work; or acquisition, analysis or interpretation of data,
- Drafted the article or revised it critically for important intellectual content,
- Approved the version to be published,
- Each author should have participated sufficiently in the work to take public responsibility for appropriate portions of the content.

Authors should meet the conditions of all of the points above. When a large, multicentre group has conducted the work, the group should identify the individuals who accept direct responsibility for the manuscript. These individuals should fully meet the criteria for authorship.

Acquisition of funding, collection of data, or general supervision of the research group alone does not constitute authorship, although all contributors who do not meet the criteria for authorship should be

listed in the Acknowledgments section. Please refer to the [International Committee of Medical Journal Editors \(ICMJE\) authorship guidelines](#) for more information on authorship.

### **2.3 Acknowledgements**

All contributors who do not meet the criteria for authorship should be listed in an Acknowledgements section. Examples of those who might be acknowledged include a person who provided purely technical help, or a department chair who provided only general support.

Any acknowledgements should appear first at the end of your article prior to your Declaration of Conflicting Interests (if applicable), any notes and your References.

### **2.4 Funding**

Clinical Rehabilitation requires all authors to acknowledge their funding in a consistent fashion under a separate heading. Please visit the [Funding Acknowledgements](#) page on the SAGE Journal Author Gateway to confirm the format of the acknowledgment text in the event of funding, or state that: This research received no specific grant from any funding agency in the public, commercial, or not-for-profit sectors.

### **2.5 Declaration of conflicting interests**

It is the policy of Clinical Rehabilitation to require a declaration of conflicting interests from all authors enabling a statement to be carried within the paginated pages of all published articles.

Please ensure that a 'Declaration of Conflicting Interests' statement is included at the end of your manuscript, after any acknowledgements and prior to the references, under a heading 'Conflict of Interest Statement'. If no conflict exists, please state that 'The Author(s) declare(s) that there is no conflict of interest'. For guidance on conflict of interest statements, please see the ICMJE recommendations [here](#).

When making a declaration, the disclosure information must be specific and include any financial relationship that all authors of the article have with any sponsoring organization and the for-profit interests that the organisation represents, and with any for-profit product discussed or implied in the text of the article.

Any commercial or financial involvements that might represent an appearance of a conflict of interest need to be additionally disclosed in the covering letter accompanying your article to assist the Editor in evaluating whether sufficient disclosure has been made within the Conflict of Interest statement provided in the article.

### **2.6 Research ethics and patient consent**

Medical research involving human subjects must be conducted according to the [World Medical Association Declaration of Helsinki](#)

Submitted manuscripts should conform to the [ICMJE Recommendations for the Conduct, Reporting, Editing, and Publication of Scholarly Work in Medical Journals](#), and all papers reporting animal and/or human studies must state in the methods section that the relevant Ethics Committee or Institutional Review Board provided (or waived) approval. Please ensure that you have provided the full name and institution of the review committee, in addition to the approval number.

For research articles, authors are also required to state in the methods section whether participants provided informed consent and whether the consent was written or verbal.

Information on informed consent to report individual cases or case series should be included in the manuscript text. A statement is required regarding whether written informed consent for patient information and images to be published was provided by the patient(s) or a legally authorized representative.

Please also refer to the [ICMJE Recommendations for the Protection of Research Participants](#)

## **2.7 Reporting guidelines**

The relevant [EQUATOR Network](#) reporting guidelines should be followed depending on the type of study. For example, all randomized controlled trials submitted for publication should include a completed [CONSORT](#) flow chart as a cited figure and the completed CONSORT checklist should be uploaded with your submission as a supplementary file. Systematic reviews and meta-analyses should include the completed [PRISMA](#) flow chart as a cited figure and the completed PRISMA checklist should be uploaded with your submission as a supplementary file. The [EQUATOR wizard](#) can help you identify the appropriate guideline. Clinical Rehabilitation expects all clinical trials to be registered with a [recognised registry](#), and the name of the registry and the registration number to be given in the paper, usually in the first paragraph in the methods section.

Other resources can be found at [NLM's Research Reporting Guidelines and Initiatives](#)

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## **3. Publishing Policies**

### **3.1 Publication ethics**

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### **3.3 Open access and author archiving**

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## **4. Preparing your manuscript for submission**

### **4.1 Formatting**

The preferred format for your manuscript is Word. LaTeX files are also accepted.

### **4.2 Artwork, figures and other graphics**

For guidance on the preparation of illustrations, pictures and graphs in electronic format, please visit SAGE's [Manuscript Submission Guidelines](#).

Figures supplied in colour will appear in colour online regardless of whether or not these illustrations are reproduced in colour in the printed version. For specifically requested colour reproduction in print, you will receive information regarding the costs from SAGE after receipt of your accepted article.

### **4.3 Supplementary material**

This journal is able to host additional materials online (e.g. datasets, podcasts, videos, images etc) alongside the full-text of the article. For more information please refer to our [guidelines on submitting supplementary files](#).

### **4.4 Reference style**

Clinical Rehabilitation adheres to the SAGE Vancouver reference style. View the [SAGE Vancouver guidelines](#) to ensure your manuscript conforms to this reference style.

If you use [EndNote](#) to manage references, you can download the [SAGE Vancouver EndNote output file](#).

### **4.5 English language editing services**

Authors seeking assistance with English language editing, translation, or figure and manuscript formatting to fit the journal's specifications should consider using SAGE Language Services. Visit [SAGE Language Services](#) on our Journal Author Gateway for further information.

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## **5. Submitting your manuscript**



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**IMPORTANT:** Please check whether you already have an account in the system before trying to create a new one. If you have reviewed or authored for the journal in the past year it is likely that you will have had an account created. For further guidance on submitting your manuscript online please visit ScholarOne Online Help.

## 5.1 ORCID

As part of our commitment to ensuring an ethical, transparent and fair peer review process SAGE is a supporting member of ORCID, the Open Researcher and Contributor ID. ORCID provides a unique and persistent digital identifier that distinguishes researchers from every other researcher, even those who share the same name, and, through integration in key research workflows such as manuscript and grant submission, supports automated linkages between researchers and their professional activities, ensuring that their work is recognized.

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## 5.2 Information required for completing your submission

You will be asked to provide contact details and academic affiliations for all co-authors via the submission system and identify who is to be the corresponding author. These details must match what appears on your manuscript. At this stage please ensure you have included all the required statements and declarations and uploaded any additional supplementary files (including reporting guidelines where relevant).

### 5.2.1 Publication of twitter handles:

As a way of encouraging ongoing discussion within the field, *Clinical Rehabilitation* authors are offered the option of providing their Twitter handle to be published alongside their name and email address within their article. This way, *Clinical Rehabilitation* readers who have questions or thoughts regarding your paper can tweet you directly. Providing a Twitter handle for publication is entirely optional, if you are not comfortable with *Clinical Rehabilitation* promoting your article along with your personal Twitter handle then please do not supply it.

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Joe Bloggs, Department of Clinical Rehabilitation, Clinical Rehabilitation Hospital, Town, ST1 345, UK.  
Email: [JoeBloggs@email.com](mailto:JoeBloggs@email.com)  
Twitter: @drjoebloggs

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## **6. On acceptance and publication**

### **6.1 SAGE Production**

Your SAGE Production Editor will keep you informed as to your article's progress throughout the production process. Proofs will be sent by PDF to the corresponding author and should be returned promptly. Authors are reminded to check their proofs carefully to confirm that all author information, including names, affiliations, sequence and contact details are correct, and that Funding and Conflict of Interest statements, if any, are accurate. Please note that if there are any changes to the author list at this stage all authors will be required to complete and sign a form authorising the change.

### **6.2 Online First publication**

Online First allows final articles (completed and approved articles awaiting assignment to a future issue) to be published online prior to their inclusion in a journal issue, which significantly reduces the lead time between submission and publication. Visit the [SAGE Journals help page](#) for more details, including how to cite Online First articles.

### **6.3 Access to your published article**

SAGE provides authors with online access to their final article.

### **6.4 Promoting your article**

Publication is not the end of the process! You can help disseminate your paper and ensure it is as widely read and cited as possible. The SAGE Author Gateway has numerous resources to help you promote your work. Visit the [Promote Your Article](#) page on the Gateway for tips and advice. In addition, SAGE is partnered with Kudos, a free service that allows authors to explain, enrich, share, and measure the impact of their article. Find out how to [maximise your article's impact with Kudos](#).

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## **7. Further information**

### **7.1 Important 'Instructions to Authors' – from the Editor**

Further specific advice on editorial aspects of the journal and of writing for the journal are also available."

## ***Appendix 2. Studies excluded due to duplication of Participant Data***

A'Campo, L., Wekking, E., Spliethoff-Kamminga, N., Stijnen, T., & Roos, R. (2011). Treatment effect modifiers for the patient education programme for Parkinson's disease. *International Journal of Clinical Practice*, 66(1), 77-83.

Durland, J.L. (2017). *Telephone-based cognitive behavioral therapy for depression In Parkinson's disease: Four pragmatic cases*. Doctoral thesis, The State University of New Jersey. Available at <https://rucore.libraries.rutgers.edu/etd/>

Simons, G., Thompson, S., & Smith Pasqualini, M. (2006). An innovative education programme for people with Parkinson's disease and their carers. *Parkinsonism & Related Disorders*, 12(8), 478-485.

Trend, P., Kaye, J., Gage, H., Owen, C., & Wade, D. (2002). Short-term effectiveness of intensive multidisciplinary rehabilitation for people with Parkinson's disease and their carers. *Clinical Rehabilitation*, 16(7), 717-725.

### ***Appendix 3. Quality Appraisal Tools and Scoring***

The Effective Public Health Practice Project (EPHPP) Quality Assessment Tool was used in full, with rating undertaken as guided within the EPHPP dictionary. Both the EPHPP Quality Assessment Tool and EPHPP Dictionary are available from;

[https://merst.ca/wp-content/uploads/2018/02/quality-assessment-tool\\_2010.pdf](https://merst.ca/wp-content/uploads/2018/02/quality-assessment-tool_2010.pdf)

[https://merst.ca/wp-content/uploads/2018/02/quality-assessment-dictionary\\_2017.pdf](https://merst.ca/wp-content/uploads/2018/02/quality-assessment-dictionary_2017.pdf)

The *intervention integrity* and *analysis* components within in the EPHPP were provided ratings, however, these ratings did not impact on the Global Rating for the EPHPP. Two additional quality appraisal components to assess quality of reporting and generalisability were designed for this study. The following outlines how ratings were derived for these components;

#### **INTERVENTION INTEGRITY**

STRONG	More than 80% of participants received the allocated intervention AND consistency of the intervention was measured AND unlikely that participants received an unintended intervention
MODERATE	More than 60% of participants received the allocated intervention AND unlikely that participants received an unintended intervention
WEAK	Less than 40% of participants received the allocated intervention AND/OR likely participants received an unintended intervention

#### **ANALYSIS**

STRONG	Statistical methods appropriate for the study AND intention-to-treat analysis undertaken
MODERATE	Statistical methods appropriate for the study
WEAK	Statistical methods not appropriate for the study

## QUALITY OF REPORTING

Adherence to statement guidelines for reporting (CONSORT for RCT's, TREND for nonrandomised designs, STROBE for observational designs)

STRONG	Reporting of the article strictly followed the relevant statement guideline.
MODERATE	Reporting of the article covers all required sections outlined by the guidelines, however, some aspects outlined in guidelines missing but these aspects would not impact on assessing risk of bias and replication of the study.
WEAK	Does not appear to follow the guidelines and/or does not report on major sections required by the guidelines.
NOT APPLICABLE	Study design does not require that it adheres to guidelines (TREND, CONSORT and STROBE).

## GENERALISABILITY

Intervention implemented in a way that would be considered routine practice for this population

STRONG	The settings where the participants were recruited and delivered from were representative of the settings where an intervention would be received e.g. recruitment settings include clinical/community setting and delivery setting include clinical/community/home setting.
MODERATE	The article discusses generalisability to a clinical/community setting, however, does not take place in these settings.
WEAK	The article does not discuss generalisability AND intervention takes place within a setting not considered routine practice (e.g. research) or setting not reported.

## ***Appendix 4. Psychology & Health Author Guidelines***

*The following outlines the author guidelines, quoted and accessed from;*  
[https://www.tandfonline.com/action/authorSubmission?show=instructions&journalC  
ode=gphsh20](https://www.tandfonline.com/action/authorSubmission?show=instructions&journalCode=gphsh20)

"Instructions for authors

Thank you for choosing to submit your paper to us. These instructions will ensure we have everything required so your paper can move through peer review, production and publication smoothly. Please take the time to read and follow them as closely as possible, as doing so will ensure your paper matches the journal's requirements. For general guidance on the publication process at Taylor & Francis please visit our Author Services website.



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This journal uses ScholarOne Manuscripts (previously Manuscript Central) to peer review manuscript submissions. Please read the guide for ScholarOne authors before making a submission. Complete guidelines for preparing and submitting your manuscript to this journal are provided below.

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Please note that this journal only publishes manuscripts in English.

*Psychology & Health* accepts the following types of article: Article, Editorial, Commentary, Registered Reports.

Registered Reports differ from conventional empirical articles by performing part of the review process before the researchers collect and analyse data. Unlike more conventional process where a full report of empirical research is submitted for peer review, RRs can be considered as proposals for empirical research, which are evaluated on their merit prior to the data being collected. For information on how to prepare Registered Reports (RR) submissions please see [here](#).

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Taylor & Francis is committed to peer-review integrity and upholding the highest standards of review. Once your paper has been assessed for suitability by the editor, it will then be single blind peer reviewed by independent, anonymous expert referees. Find out more about what to expect during peer review and read our guidance on publishing ethics.

Preparing Your Paper

Structure

Your paper should be compiled in the following order: title page; abstract; keywords; main text introduction, materials and methods, results, discussion; acknowledgments; declaration of interest statement; references; appendices (as appropriate); table(s) with caption(s) (on individual pages); figures; figure captions (as a list).

Word Limits

Article and Editorial: 30 Pages

Commentary: 1000 words.

Style Guidelines

Please refer to these quick style guidelines when preparing your paper, rather than any published articles or a sample copy.

Please use British (-ise) spelling style consistently throughout your manuscript.

Please use single quotation marks, except where 'a quotation is "within" a quotation'. Please note that long quotations should be indented without quotation marks.

Formatting and Templates

Papers may be submitted in Word format. Figures should be saved separately from the text. To assist you in preparing your paper, we provide formatting template(s).

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If you are not able to use the template via the links (or if you have any other template queries) please contact us [here](#).

## References

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An EndNote output style is also available to assist you.

## Checklist: What to Include

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Should contain a structured abstract of 200 words. Objective, Design, Main Outcome Measures, Results, Conclusion.

You can opt to include a video abstract with your article. Find out how these can help your work reach a wider audience, and what to think about when filming.

Read making your article more discoverable, including information on choosing a title and search engine optimization.

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This work was supported by the [Funding Agency] under Grant [number xxxx].

### *For multiple agency grants*

This work was supported by the [Funding Agency #1] under Grant [number xxxx]; [Funding Agency #2] under Grant [number xxxx]; and [Funding Agency #3] under Grant [number xxxx].

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**Tables.** Tables should present new information rather than duplicating what is in the text. Readers should be able to interpret the table without reference to the text. Please supply editable files.

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**Units.** Please use SI units (non-italicized).

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*Updated 23-05-2018"*

## Appendix 5. Research Ethics Committee Approval



### Health Research Authority

#### South West - Cornwall & Plymouth Research Ethics Committee

Level 3  
Block B  
Whitefriars  
Lewins Mead  
Bristol  
BS1 2NT

**Please note: This is the favourable opinion of the REC only and does not allow the amendment to be implemented at NHS sites in England until the outcome of the HRA assessment has been confirmed.**

07 September 2018

Ms Lorna Hodge  
NHS Lothian  
Lower Ground Floor, Out-patient Building  
Western General Hospital, Crewe Road South, Edinburgh  
EH4 2XU

Dear Ms Hodge

<b>Study title:</b>	<b>Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion.</b>
<b>REC reference:</b>	<b>18/SW/0113</b>
<b>Protocol number:</b>	<b>CAHSS1802/02</b>
<b>Amendment number:</b>	<b>Amendment 1,</b>
<b>Amendment date:</b>	<b>07 August 2018</b>
<b>IRAS project ID:</b>	<b>234330</b>

The above amendment was reviewed at the meeting of the Sub-Committee held on 31 August 2018 by the Sub-Committee in correspondence.

#### Summary

This amendment sought to correct the inclusion criteria.

#### Ethical opinion

The members of the Committee taking part in the review gave a favourable ethical opinion of the amendment on the basis described in the notice of amendment form and supporting documentation.

#### Approved documents

The documents reviewed and approved at the meeting were:

Document	Version	Date
Notice of Substantial Amendment (non-CTIMP)		07 August 2018
Research protocol or project proposal	3.0	07 August 2018

#### Membership of the Committee

The members of the Committee who took part in the review are listed on the attached sheet.

#### Working with NHS Care Organisations

Sponsors should ensure that they notify the R&D office for the relevant NHS care organisation of this amendment in line with the terms detailed in the categorisation email issued by the lead nation for the study.

#### Statement of compliance

The Committee is constituted in accordance with the Governance Arrangements for Research Ethics Committees and complies fully with the Standard Operating Procedures for Research Ethics Committees in the UK.

We are pleased to welcome researchers and R & D staff at our Research Ethics Committee members' training days – see details at <http://www.hra.nhs.uk/hra-training/>

<b>18/SW/0113:</b>	<b>Please quote this number on all correspondence</b>
--------------------	---

Yours sincerely



**Canon Ian Ainsworth-Smith**

**Chair**

E-mail: [nrescommittee.southwest-cornwall-plymouth@nhs.net](mailto:nrescommittee.southwest-cornwall-plymouth@nhs.net)

*Enclosures: List of names and professions of members who took part in the review*

*Copy to: Miss Melissa Taylor, NHS Lothian Research & Development Office  
Ms Lorna Hodge*

## Appendix 6. Research & Development Approval

### University Hospitals Division

Queen's Medical Research Institute  
47 Little France Crescent, Edinburgh, EH16 4TJ

DY/CK/approval

29 May 2018

Ms Lorna Hodge  
Lower Ground Floor,  
Out-patient Building  
Western General Hospital,  
Crewe Road South  
Edinburgh  
EH4 2XU



Research & Development  
Room E1.16  
Tel: 0131 242 3330

Email:  
accord@nhslothian.scot.nhs.uk

Director: Professor Tim Walsh

Dear Ms Hodge

**Lothian R&D Project No:** 2018/0153

**REC No:** 18/SW/0113

**Title of Research:** Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion

**Participant Information Sheet: (PwPD, Care Givers)**  
Version 2.0, dated 26 April 2018

**Consent Form: (PwPD, Care Givers)**  
Version 2.0, dated 26 April 2018

**Protocol:** CAHSS1802/02, Version 2.0, dated 26 April 2018

I am pleased to inform you this letter provides Site Specific approval for NHS Lothian for the above study and you may proceed with your research, subject to the conditions below.

Please note that the NHS Lothian R&D Office must be informed of any changes to the study such as amendments to the protocol, funding, recruitment, personnel or resource input required of NHS Lothian.


Substantial amendments to the protocol will require approval from the ethics committee which approved your study and the MHRA where applicable.

Please keep this office informed of the following study information, **which is a condition of NHS Lothian R&D Management Approval:**

1. Date you are ready to begin recruitment, date of the recruitment of the first participant and the monthly recruitment figures thereafter.
2. Date the final participant is recruited and the final recruitment figures.
3. Date your study / trial is completed within NHS Lothian.

I wish you every success with your study.

Yours sincerely

  
**Dr Douglas Young**  
Principal R&D Manager

Cc: Michael Pearson, General Manager, Royal Infirmary of Edinburgh

## Appendix 6. Research & Development Approval Continued

NHS Lanarkshire Research & Development: PICApprovalLetter\_V2.1\_100518

Project I.D. Number: L18086\_PIC



Ms Lorna Hodge  
Trainee Clinical Psychologist  
NHS Lothian  
Lower Ground Floor, Out-patient Building  
Western General Hospital  
Crewe Road South  
Edinburgh  
EH4 2XU

R&D Department  
Corporate Services Building  
Monklands Hospital  
Monkscourt Avenue  
AIRDRIE  
ML6 0JS

Date	21.12.18
Enquiries to	Elizabeth McGonigal, R&D Facilitator
Direct Line	01236 712459
Email	elizabeth.mcgonigal@lanarkshire.scot.nhs.uk

Dear Ms Hodge

**R&D ID: L18086\_PIC**

**NRS Number: NRS18/234330**

**PROJECT TITLE: Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion**

I am writing to you as Chief Investigator of the above study to advise that R&D Permission has been given for NHS Lanarkshire to act as a Participant Identification Centre (PIC) that will refer potential subjects to Ms Hodge in NHS Lothian. The local contact is Dr Laura Peacock.

NOTE: As a PIC, NHS Lanarkshire's involvement in the study is strictly limited to identifying and referring potential participants to the study team in NHS Lothian for assessment and possible recruitment into the study.

NHS Lanarkshire staff are not authorised to carry out any other study related procedures such as taking consent, carrying out investigations, taking samples, etc. – all such activities must be carried out at NHS Lothian.

For the study to be carried out you are subject to the following conditions:

L18086\_PIC\_ManagementApproval\_211218

Cont/...  
Page 1 of 2

Conditions

- You are required to comply with Good Clinical Practice, Ethics Guidelines, Health & Safety Act 1999 and relevant UK and EU Data Protection legislation.
- The research is carried out in accordance with the Scottish Executive's Research Governance Framework for Health and Community Care (copy available via the Chief Scientist Office website: <http://www.cso.scot.nhs.uk/> or the Research & Development Intranet site: <http://firstport2/staff-support/research-and-development/default.aspx>
- You must ensure that all confidential information is maintained in secure storage. You are further obligated under this agreement to report to the NHS Lanarkshire Data Protection Office and the Research & Development Office infringements, either by accident or otherwise, which constitutes a breach of confidentiality.
- Clinical trial agreements (if applicable), or any other agreements in relation to the study, have been signed off by all relevant signatories.
- You must contact the Lead Nation Coordinating Centre if/when the project is subject to any minor or substantial amendments so that these can be appropriately assessed, and approved, where necessary.
- You notify the R&D Department if any additional researchers become involved in the project within NHS Lanarkshire.
- You notify the R&D Department when you have completed your research, or if you decide to terminate it prematurely.
- You must send brief annual reports followed by a final report and summary to the R&D office in hard copy and electronic formats as well as any publications.
- If the research involves any investigators who are not employed by NHS Lanarkshire, but who will be dealing with NHS Lanarkshire patients, there may be a requirement for a criminal records check. If this is the case then please contact the R&D Department to discuss.

I trust these conditions are acceptable to you.

Yours sincerely,

Raymond Hamill, Senior Research & Development Manager

CC.

NAME	TITLE	CONTACT ADDRESS	ROLE
Dr Laura Peacock		<a href="mailto:Laura.Peacock@lanarkshire.scot.nhs.uk">Laura.Peacock@lanarkshire.scot.nhs.uk</a>	Local Contact
Ms Charlotte Smith		<a href="mailto:Charlotte.smith@ed.ac.uk">Charlotte.smith@ed.ac.uk</a>	Sponsor Contact
Leigh Nicholson	Parkinson's Specialist Nurses	<a href="mailto:Leigh.Nicholson@lanarkshire.scot.nhs.uk">Leigh.Nicholson@lanarkshire.scot.nhs.uk</a>	Named Contact
Christine McBrearty		<a href="mailto:Christine.McBrearty@lanarkshire.scot.nhs.uk">Christine.McBrearty@lanarkshire.scot.nhs.uk</a>	



## Appendix 6. Research & Development Approval Continued



25 May 2018

Ms Lorna Hodge  
NHS Lothian  
Lower Ground Floor, Out-patient Building  
Western General Hospital, Crewe Road South  
Edinburgh  
EH4 2XU

Dear Ms Hodge,

### PIC APPROVAL LETTER – NHS TAYSIDE

**Title:** Psychological adjustment in people with Parkinson's disease and caregivers; the role of coping, illness beliefs and self-compassion

**Chief Investigator:** Ms Lorna Hodge

**Local Collaborator:** Dr Esther Sammler

**Tayside Ref:** 2018NF06    **NRS Ref:** NRS18/234330

**REC Ref:** 18/SW/0113

**Sponsor:** NHS Lothian / University of Edinburgh

**Funder:** Student project – no external funding

Many thanks for your request for NHS Tayside to act as a Participant Identification Centre (PIC) for the above study. I am pleased to confirm that the project documentation (as outlined below) has been reviewed, registered and Management Approval has been granted for NHS Tayside to act as a PIC in this case.

Approval is granted on the following conditions:-

- NHS Tayside is a Participant Identification Centre (PIC) only and is not a Research Site for this study.
- ALL Research must be carried out in compliance with the Research Governance Framework for Health & Community Care, Health & Safety Regulations, data protection principles, statutory legislation and in accordance with Good Clinical Practice (GCP).
- As custodian of the information collated during this research project you are responsible for ensuring the security of all personal information collected in line with NHS Scotland IT Security Policies, until destruction of this data.
- Notification of early termination within 15 days or End of Trial within 90 days followed by End of Trial Report within 1 year to TASC R&D Office.

Please note you are required to adhere to the conditions, if not, NHS Tayside PIC approval may be withdrawn for the study.

**Approved Documents**

Document	Version	Date
IRAS		
SSI		
Sponsor insurance		26/07/2017
Invitation Letter	2	26/04/2017
Invitation Letter (care giver)	1	06/04/2017
Non-validated questionnaire	1	06/04/2017
Non-validated questionnaire (cover questionnaire pack PwPD)	1	26/04/2017
Non-validated questionnaire (cover questionnaire pack C G )	2	26/04/2017
Consent form	2	26/04/2017
Consent form (C G)	2	26/04/2017
Participant Information Sheet (PwPD)	2	26/04/2017
Participant Information Sheet (C G)	2	26/04/2017
Protocol	2	26/04/2016
Study Flowchart	1	06/04/2017

May I take this opportunity to wish you every success with your project.

Please do not hesitate to contact TASC R&D Office should you require further assistance.



Yours sincerely

  
Elizabeth Coote  
Head of Non-Commercial Research Services

Tayside medical Science Centre (TASC)  
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Psychological adjustment in people affected by Parkinson's disease  
Version 3, 07/08/18  
IRAS ID: 234330



**Study Protocol**

Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion.

**Version 3**  
**Date: 07/08/18**

Principal Investigator  
**Ms Lorna Hodge**

Supervisors  
**Dr Azucena Guzmán**  
**Dr Liz Baikie**

1 of 22

Psychological adjustment in people affected by Parkinson's disease  
Version 3, 07/08/18  
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Protocol authors	Ms Lorna Hodge Dr Azucena Guzmán Dr Liz Baikie
Chief Investigator	Ms Lorna Hodge, Trainee Clinical Psychologist
REC Number	18/SW/0113
Version Number and Date	Version 3, 7 <sup>th</sup> August 2018

**LIST OF ABBREVIATIONS**

AC-QoL	Adult Carer Quality of Life Questionnaire
Brief-IPQ	Brief Illness Perception Questionnaire
HADS	Hospital Anxiety and Depression Scale
NHS	National Health Service
PD	Parkinson's disease
PDQ-8	Parkinson's disease Questionnaire 8-item version
REC	Research Ethics Committee
UK	United Kingdom

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## 1 INTRODUCTION

### 1.1 BACKGROUND

Parkinson's disease (PD) is a condition that damages parts of the brain progressively over time (Parkinson's UK, 2014). PD develops due to the death of nerve cells which are responsible for the production of the organic chemical dopamine. Within the brain dopamine acts as a neurotransmitter, which has several functions including transferring messages to the areas of brain where movement is coordinated (Parkinson's UK, 2014). Due to the reduced activity of the dopamine-secreting cells within people with PD, several primary symptoms develop such as rigidity, bradykinesia, tremors and postural instability (Evans & Norman, 2009). People with PD can also experience psychological difficulties and poor mental health which may be as result of the primary symptoms of disease (Nut et al., 2004). However, the psychological impact of PD can be overlooked, with limited research in to the benefits of psychological interventions for people with PD (Yang et al., 2012).

It is estimated that over 10,000 people within Scotland have a diagnosis of PD, and it is predicted that there will be an increase of 28% of people with PD by 2020 (Parkinson's UK, 2009). Considering that the highest prevalence of PD is in people aged over 75 years (Parkinson's UK, 2009), and the increasing ageing population, there is an increased need for better understanding on how to best support people with PD. Caregivers of people affected by PD, who are usually family members, may be best placed to provide the support to those with PD. However, the needs of caregivers are also of importance and needs to be addressed. PD can impact on caregivers' psychological wellbeing (Glozman, 2004; Kudlicka et al., 2014; Aarsland et al., 2007). Quality of life of caregivers of people with PD are also significantly associated with the severity of the PD (Martinez-Martin et al., 2007). Considering the chronic nature and evolving symptoms of the disease, and the growing population being impacted by PD, being able to cope and adjust accordingly to the disease would be beneficial to the psychological wellbeing of all those affected.

### 1.2 RATIONALE FOR STUDY

Psychological adjustment is the rebalancing of a person to their new circumstances, as they find new coping strategies to help them adjust to their changed circumstances (de Ridder et al., 2008). When exploring psychological adjustment in illness, researchers draw on many theoretical models of living with illness, with the Common Sense Model being a well-researched example. The Common Sense Model assumes that a person's understanding and management of an illness is based on their interpretation of the information presented to them about their illness (Leventhal et al., 2016). These 'illness beliefs' have an established relationship with

psychological functioning in many chronic illnesses, including neurodegenerative disorders (Jopson & Moss-Morris, 2003; Kaptein et al., 2007). Further knowledge of these relationships within Parkinson's disease may lead to a better understanding of the appropriate interventions and/or strategies that can be provided to help those affected by PD.

Research with people with PD have demonstrated that a person's illness belief and coping of PD can be associated with psychological outcomes. Evans and Norman (2009) conducted a prospective design by a cross-sectional survey of people with PD, in which the relationship between coping, illness representations and psychological distress (in terms of anxiety and depression) were explored. They found that only three illness beliefs (i.e. personal control, consequences, and emotional representations) were associated with higher levels of psychological distress. Evans and Norman (2009) also found that the coping strategies of avoidance and resignation were associated with increased psychological distress. However, Evans and Norman (2009) did not explore whether illness beliefs and coping strategies may be associated with positive psychological outcomes such as quality of life.

Similar research by Simpson et al. (2013) explored the relationship between illness beliefs, psychological distress and quality of life in people with PD. Simpson et al. (2013) found a positive correlation between anxiety and having a higher belief in a psychosocial cause of PD. Simpson et al. (2013) also reported that a poorer understanding of PD may explain why there was a relationship between coherence and quality of life. Simpson et al. (2013) and Evans and Norman (2009) both demonstrated that some illness beliefs were related to the outcome measures. However, the beliefs related to outcomes differed in these studies, as Simpson et al. (2013) found causal beliefs and illness coherence were associated with psychological outcomes. This may have been due to Evans and Norman (2009) not testing their beliefs against more established predictors unlike Simpson et al. (2013). Furthermore, neither Simpson et al. (2013) and Evans and Norman (2009) considered the impact of PD on caregivers.

Recent research by Narvaia-Sanchez et al. (2016) explored determinants which influence psychosocial adjustment and quality of life in both people with PD and caregivers. Narvaia-Sanchez et al. (2016) found that the severity of PD was a main predictor of psychosocial adjustment and quality of life in people with PD. However, coping behaviours were found to be predictors of psychosocial adjustment in both people with PD and caregivers. Specifically, Narvaia-Sanchez et al. (2016) found that people with PD and caregivers with a greater number of coping strategies were associated with better psychosocial adjustment, therefore, highlighting the role of health professionals within clinical practice. Health professionals have the position to provide both people with PD and caregivers with information about coping responses to potentially support their psychosocial adjustment to the diagnosis of PD. However, Narvaia-Sanchez et al. (2016) did not explore the role of illness beliefs for caregivers and people with PD. Research within other populations of neurodegenerative conditions suggest illness beliefs are associated with the psychological outcomes in caregivers

Therefore, further research into factors which contribute to psychological adjustment for both people with PD and their caregivers is warranted.

An area of growing research within chronic health is self-compassion. Neff et al. (2007) reported that 'Self-compassion represents a warm and accepting stance towards those aspects of oneself and one's life that is disliked' (p908). Self-compassion also includes acting towards oneself with the kindness you would treat loved ones with when faced with adversity (Terry & Leary, 2011). Similarly, self-compassionate people recognise that difficult life circumstances are a normal part of life. Therefore, self-compassionate people perceive their problems within the perspective that everyone experiences suffering, resulting in reduced feelings of isolation (Terry & Leary, 2011). Within non-clinical populations it has been consistently found that greater self-compassion is related to lower symptoms of anxiety and depression (Pinto-Gouveia et al., 2013). Within research of people who are older, Allen et al. (2011) found that people with poorer health who respond self-compassionately to difficulties in their lives, may have better perceived well-being through their lives.

There has since been growing research exploring the links between self-compassion and psychological well-being in people with chronic ill health. Research exploring the relationship between self-compassion and psychological distress in people with chronic pain has found those with greater self-compassion presented with greater psychological functioning (Wren et al., 2012). Further research within other health populations, including cancer, chronic obstructive pulmonary disease and other chronic illness, have also demonstrated the relationship between higher self-compassion and psychological wellbeing, such as lower anxiety, lower depression and better quality of life (Pinto-Gouveia et al., 2013; Kenehtok, 2016). Schelleken et al. (2017) explored the role of self-compassion in couples facing lung cancer, finding that there was a negative association between psychological distress and self-compassion for both partners. However, Schelleken et al. (2017) explored the interaction between partners further by analysing on a dyadic level the role of self-compassion in psychological distress. Schelleken et al. (2017) found that when a person experiencing lung cancer has a partner with higher self-compassion, there was found to a lower association between their own self-compassion and distress. As a result of these findings, Schelleken et al. (2017) suggest that one partner may compensate for their partner's lower self-compassion by displaying higher self-compassion and may lead to a reduction in distress in both partners, highlighting that caregivers provide an invaluable resource to people experiencing ill health. However, research exploring the role of self-compassion in psychological adjustment in people with PD and their caregivers, has not been completed at individual and dyadic levels.

People with PD commonly experience psychological distress, such as anxiety and depression, and face ongoing difficulties with adjusting to their condition. Caregivers can also experience psychological difficulties due to caring for people with PD. Therefore, further understanding of factors which contribute to the adjustment of PD would be beneficial. An increased understanding of potential risk factors associated

Psychological adjustment in people affected by Parkinson's disease  
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with psychological difficulties can help clinicians identify people with PD and caregivers who may require additional support. Similarly, further exploration of factors such as self-compassion within PD may have clinical implications when considering potential psychological therapies that may benefit people with PD and caregivers.

## 2 STUDY OBJECTIVES

The objectives of this study are to explore whether illness beliefs and coping responses have an association with psychological adjustment (in terms of depression, anxiety and quality of life) in people with PD and caregivers, and to explore what role self-compassion may have in psychological adjustment for people with PD and caregivers at an individual and dyadic level. The following are the primary and secondary research questions and corresponding hypotheses which have been drawn from research previously outlined;

### Primary research questions

- Are illness beliefs and number of coping strategies associated with psychological adjustment in people PD?
- Are illness beliefs and number of coping strategies associated with psychological adjustment in caregivers of people with PD?

Hypothesis 1) Illness beliefs (causal beliefs, illness coherence, personal control, and consequences) and number of coping strategies will be associated with psychological adjustment (depression, anxiety and quality of life) in people with PD.

Hypothesis 2) Illness beliefs (consequences and timeline) and number of coping strategies will be associated with psychological adjustment (depression, anxiety and quality of life) in caregivers of people with PD.

### Secondary research question

- What role does self-compassion have in psychological adjustment for people with PD and their caregivers at an individual and dyadic level?

Hypothesis 3) Self-compassion will be associated with psychological adjustment (depression, anxiety and quality of life), after accounting for the variance explained by illness beliefs and coping strategies in people with PD.

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Hypothesis 4) Self-compassion will be associated with a psychological adjustment (depression, anxiety and quality of life), after accounting for the variance explained by illness beliefs and coping strategies in caregivers.

Hypothesis 5) Self-compassion of caregivers will be associated with a significant additional amount of variance in psychological adjustment (depression, anxiety and quality of life) in people with PD, after accounting for the variance explained by illness beliefs and coping strategies.

## 3 STUDY DESIGN

The study will employ a cross-sectional cohort design. A clinical sample of adults with mild idiopathic Parkinson's disease and their available caregivers will be recruited for the study. Participants will be recruited through NHS Lothian and NHS Tayside. Once ethical approval has been granted by the University of Edinburgh, NHS REC and appropriate NHS health boards, participants will be invited to complete five questionnaires. The questionnaires included will be measuring coping, quality of life, psychological distress, self-compassion and illness beliefs. These questionnaires were piloted with Parkinson's UK Patient and Public Involvement, suggesting it will take approximately 60 minutes to complete all questionnaires.

## 4 STUDY POPULATION

### 4.1 NUMBER OF PARTICIPANTS

The following minimum number of participants will be recruited from the period of May 2018 to April 2019;

- 92 participants with PD
- 77 caregivers

### 4.2 INCLUSION CRITERIA

#### *Inclusion criteria for Participants with PD*

- Confirmed diagnosis of Idiopathic Parkinson's Disease at least 6 months prior to recruitment for the study.
- Identified by the referring health professional to present with mild Parkinson's disease, meeting the criteria of stage 1 or 2 of the Hoehn and Yahr scale (see appendix 1).
- Speak, read and write proficient English

#### *Inclusion criteria for Caregivers*

- Consents to participation in the study
- The caregiver normally lives with the care receiver
- The caregiver is directly responsible for your care (for example they may provide physical and/or emotional support)
- Over the age of 18 years

#### **4.3 EXCLUSION CRITERIA**

##### *Exclusion criteria for Participants with PD*

- Diagnosis of Parkinson's disease dementia and/or of Mild-Cognitive Impairment
- Cognitive impairment which could negatively impact on their ability to provide informed consent, and understand and complete questionnaires
- Unwilling or unable to provide informed consent

##### *Exclusion criteria for Caregivers*

- Paid professional employed to care for the care receiver

## **5 PARTICIPANT SELECTION AND ENROLMENT**

### **5.1 RECRUITING PARTICIPANTS AND PROCEDURE**

Participants will be recruited within NHS Lothian and NHS Tayside. This will involve health professionals working with people with PD identifying appropriate participants (who meet the inclusion criteria). Clinician's referring to the study will be required to make a clinical judgement regarding the potential participants who are able to provide informed consent and understand and complete the questionnaires. They will also be required to use their clinical judgement to exclude participants who may have cognitive impairments.

The Parkinson's Disease Specialist Nurses within NHS Lothian and NHS Tayside have agreed to recruit participants for the study. Therefore, should they identify appropriate participants, the potential participants will be presented with an information pack. The information pack will include participant information, consent form, and a stamped addressed envelope for the participant to return the completed consent form. Once the completed consent return has been received by the participant, they will be posted the questionnaire pack and a stamped addressed envelope. Participants will also be recruited through other health professionals working within NHS Lothian with people with PD, these health professionals will also

be provided with the same information packs to be offered to potential participants. Due to the nature of Parkinson's Disease Specialist Nurses, much of their interaction with patients can be over telephone communication. Therefore, a secondary route for recruitment has been proposed. This route would involve health professionals informing potential participants of the research over the telephone, and should they consent to receiving further information they will be posted the information pack which would also include a cover letter from the referring clinician. It has been estimated that it will take approximately 10 minutes of a Clinician's time to approach a potential participant, this would include the time taken to introduce the research and to handpost the relevant materials. See appendix 2 for protocol flowchart outlining recruitment procedures.

##### *Procedure for Participants with PD*

The health professionals who approach participants with PD face-to-face will provide verbal information about the study, alongside the consent form and participant information sheet. The participants will be provided with the Chief Investigators contact details should they wish to gain further information about the study. The participants will be able to take these home for them to read and complete in their own time, and return using a stamped addressed envelope.

Participants with PD who are posted information about the research, following a telephone conversation with their referring health professional, will be given a stamped addressed envelope, consent form, cover letter and participant information sheet. The participants who receive information in the post will also be provided with the contact details for the Chief Investigator should they wish to gain further information.

Once the Chief Investigator has received completed consent forms, the participants with PD will be posted the questionnaire packs for them to complete at home, and return in the stamp addressed envelope provided.

##### *Procedure for Participants who are Caregivers*

Caregivers will be provided with an information pack (a cover letter, participant information sheet, consent form and stamped addressed envelope) once the researcher has received their care receivers consent form which indicates the care receiver has discussed the research with their caregiver and they consent to their care receiver taking part in the study. They will also be provided with the contact details for the Chief Investigator should they wish to gain further information. Once the Chief Investigator has received completed consent forms, the caregivers will be posted the questionnaire packs for them to complete at home, and return in the stamped addressed envelope provided.



Consent forms and questionnaires will be given a unique code identifier to match the participant with PD questionnaires and their corresponding caregiver. This will allow for corresponding data to be analysed as a dyad. Consent forms will be stored in separate locked filing cabinets to the completed questionnaires within the researcher's clinical base within NHS Lothian. Therefore, the data collected from the questionnaires will remain anonymous.

## 5.2 CONSENTING PARTICIPANTS

Participants with Parkinson's disease and caregivers will be provided with a consent form when completing the questionnaires.

### 5.2.1 Withdrawal of Study Participants

Should a participant wish to have their data removed from the research, then they are able to inform the researcher over the telephone during the period of data collection (May 2018–April 2019) for the removal of their data from the research.

## 6 DATA COLLECTION

### 6.1 Source Data Documentation

#### Demographic Information

A short self-report questionnaire asking for demographic information and health information will be collected. Health information including age, education, civil status, previous occupation, comorbid health conditions, current medication and length of time since diagnosis of PD.

Socio-economic status will be collected through the Scottish Index of Multiple Deprivation using postcodes (Scottish Government, 2016)

The following provides an outline of the questionnaires proposed for the study;

Questionnaires for Participants with PD	Questionnaires for Caregivers
<ul style="list-style-type: none"> <li>• Brief COPE</li> <li>• Self-Compassion Scale</li> <li>• Parkinson's Disease Questionnaire</li> <li>• Hospital Anxiety and Depression Scale</li> <li>• The Brief Illness Perception Questionnaire</li> </ul>	<ul style="list-style-type: none"> <li>• Brief COPE</li> <li>• Self-Compassion Scale</li> <li>• Adult Carers Quality of Life Questionnaire</li> <li>• Hospital Anxiety and Depression Scale</li> <li>• The Brief Illness Perception Questionnaire (adapted for the study)</li> </ul>

#### Coping Strategies

##### Brief COPE Scale – Carver (1989)

The Brief COPE is a 28-item self-report which measures different coping responses. It has been separated into the following 14 scales of coping behaviours; self-distraction, active coping, humour, use of emotional support, use of instrumental support, denial, venting, behavioural disengagement, substance misuse, positive reframing, planning, acceptance, religion and self-blame. The Brief COPE has been used within research for people with PD and caregivers (Navarra-Sánchez *et al.*, 2016) and has been shown to be a reliable and valid measure within other health populations (Yusoff *et al.*, 2010). This measure takes 10 minutes to complete.

##### Self-Compassion

##### Self-Compassion Scale – Neff (2003)

The Self-Compassion Scale is 26-item self-report scale of self-compassion. The measure asks participants to answer each question on a 5-point Likert scale from "almost never" to "almost always" in relation to how they act towards themselves during difficult times. The questions are spread across 6 subscales which are; self-kindness, common humanity, isolation, self-judgement, over-identification and mindfulness. Research indicates that this scale has good internal validity and test-retest reliability (Neff, 2003; Neff & McGehee, 2010; Przedziecki *et al.*, 2013). This measure takes 10 minutes to complete.

##### Quality of Life

##### Parkinson's disease questionnaire-8 item version (PDQ-8) – Jenkinson *et al.* (1997)

The PDQ-8 is a shortened version of the Parkinson's disease questionnaire-39 item (PDQ-39) self-report scale of quality of life for people with PD (Peto *et al.*, 1995). The PDQ-39 demonstrates good content validity, construct validity and acceptable internal consistency and test-retest reliability (Marinus *et al.*, 2002b; Tan *et al.*, 2004). The PDQ-8 has been shown to be a valid and reliable measure of quality of life (Tan *et al.*, 2007). To minimise test burden, the PDQ-8 will be used for participants with PD. The PDQ-8 has eight subscales assessing the following: activities of daily living, mobility, emotional wellbeing, stigma, cognitions, social support, communication, and bodily discomfort. This measure takes 4 minutes to complete.

##### Adult Carer Quality of Life Questionnaire (AC-QoL) – Joseph *et al.* (2012)

The AC-QoL is a 40-item self-report questionnaire measuring quality of life in caregivers in the following eight domains; sense of value, support for caring, money matters, caring choice, caring stress, ability to care, personal growth and carer satisfaction. The AC-QoL has been found to have excellent consistency reliability (Joseph *et al.*, 2012; Brand *et al.*, 2016). This measure takes 10 minutes to complete.



## Distress

### Hospital Anxiety and Depression Scale (HADS) – Snaith & Zigmond (1988)

The HADS is a 14-item self-report questionnaire containing 7 items measuring anxiety and 7 items measuring depression. The scores for anxiety and depression are not confounded by physical symptoms associated with illness as the scale does not measure somatic symptomatology (Evans & Norman, 2009). HADS has been shown to be a validated measure with good test-retest reliability and has previously been used within similar research exploring distress in people with PD (Evans & Norman, 2009; Marinus *et al.*, 2002a) as well as caregivers (Schellekens *et al.*, 2017). This measure takes 5 minutes to complete.

## Illness Beliefs

### The Brief Illness Perception Questionnaire (Brief-IPQ) – Broadbent *et al.* (2006)

The Brief-IPQ is a self-report questionnaire used to measure a participant's belief about their illness. The Brief-IPQ is adapted from the Illness Perception Questionnaire (IPQ-R) developed by Moss-Morris *et al.* (2002) which was theoretically based on Leventhal *et al.*'s (1984) model of illness representations. The Brief-IPQ statements are rated by participants on a Likert scale from 0-10, and each statement corresponds to the following dimensions: perceived consequences, identity, perceived personal control, treatment control, concerns about the illness, coherence of the illness, timeline (acute-chronic) and emotional representation (Broadbent *et al.*, 2015). The Brief-IPQ has moderate to good correlations on concurrent validity, and good test-retest reliability (Broadbent *et al.*, 2006). The Brief-IPQ given to caregivers will be adapted by phrasing questions from 'my illness' to 'Parkinson's disease'. This approach has been demonstrated as effective within other research when seeking illness representations for caregivers (Bassi *et al.*, 2016). The full Brief-IPQ will be administered to participants (Participants with PD and caregivers), however, based on previous research the predictor outcomes are expected to be the following subscales: personal control, consequences, causal beliefs, and illness coherence (Evans & Norman, 2009; Simpson *et al.*, 2013) for participants with PD. In line with research by Kaptein *et al.* (2007) the subscales expected to be predictors for caregivers are consequences and timeline. The subscale of emotional representation may overlap with the outcome measures (HADS), therefore, will also not be included within analysis. This measure takes 5 minutes to complete.

## 7 STATISTICS AND DATA ANALYSIS

### 7.1 SAMPLE SIZE CALCULATION

#### Sample size for Participants with PD

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Sample size for participants with PD based on the primary research question 'Are illness beliefs and number of coping strategies associated with psychological adjustment in people Parkinson's disease?'. A-priori sample size calculations have been made for multiple regression analysis. There are five predictors proposed for the first primary research questions (number of coping responses and the four subscales of illness representations).

The study by Evans & Norman (2009) with a sample of 58 participants reported that following regression analyses that illness representations, measured by sum score of the revised Illness Perception Questionnaire, explained 42% variance in anxiety and 44% in depression. Research by Navata-Sanchez *et al.* (2016), with a sample of 91 participants with PD, found medium effect sizes for coping responses accounting for variance in psychosocial adjustment in people with PD.

Therefore, based on previous research and the proposed hypothesis, at least a medium effect size will be expected. Based on Cohen's (1992) recommendation for detecting medium effect size, with a power of 0.8 and a significance level of 0.05 the sample size was calculated using G\*Power. A sample size for linear multiple regression analyses with up to five predictors was computed. The sample size computed by G\*Power was a minimum of 92 to detect a medium effect size.

#### Sample size for Caregivers

Sample size for caregivers are based on the primary research question 'Are illness beliefs and number of coping strategies associated with psychological adjustment in caregivers?'. A-priori sample size calculations have been made for multiple regression analyses. There are three predictors proposed for the hypothesis (number of coping responses and two subscales of illness representations).

The study by Navata-Sanchez *et al.* (2016), with a sample of 83 caregivers, found medium effect sizes for number of coping responses accounting for variance in psychosocial adjustment in caregivers. There has been no research completed with caregivers of people with PD and the association between illness beliefs and psychological adjustment, however, Kaptein *et al.* (2007) conducted similar research with people with Huntington's disease and partners. For relationships between illness representation (timeline and consequences) and quality of life (including a subscale for mental health) in a sample of 51 couples, Kaptein *et al.* (2007) reported correlations between 0.29-0.40. Considering the correlations and effect sizes outlined in previous research, a conservative medium effect size of 0.3 was selected when calculating the a-priori sample size. Based on Cohen's (1992) recommendation for detecting medium effect size, with a power of 0.8 and a significance level of 0.05 the sample size was calculated using G\*Power. Sample size for linear multiple regression analyses with up to three predictors was computed. The sample size computed by G\*Power was a minimum of 77 to detect a medium effect size.

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**As outlined above, the minimum sample size required would be 92 participants with PD and 77 caregivers.**

The Parkinson's Disease Specialists Nurse Service within NHS Lothian have reported that on average there are 160 new diagnoses of PD per year within NHS Lothian, and in 2016 it was reported that they had an estimated 1800 people on their caseload. Both the lead for the Parkinson's Disease Specialist Service within NHS Lothian and the Neurological Service within NHS Tayside report that it would be possible to meet the required sample size over a six month period.

Both these services have reported that there is a good response rate in research within this population. Similar research within the UK with people with PD have reported a response rate between 51-75% (Simpson et al., 2013; Evans and Norman, 2009). Whereas, research within UK recruiting people with PD and their corresponding identified caregivers have reported an 80% response rate for caregivers willing to take part (Leroi et al., 2012).

Additional measures that will be taken to reduce the risk of meeting the sample size include recruiting further participants through other health professionals within NHS Lothian and NHS Tayside (e.g. health professionals working within Neurology and Medicine of the Elderly).

## 7.2 STATISTICAL ANALYSES

Descriptive analysis will be used to report demographic information. Relationships between demographics will be assessed through independent sample t-tests. All data will be tested for normal distribution using the Kolmogorov-Smirnov test.

### Primary Research Questions

In addressing the primary research question "Are illness beliefs and number of coping strategies associated with psychological adjustment in people PD?" preliminary correlational analysis will be used to identify any significant associations between variables. Multiple-regression analysis will be undertaken to explore the association of illness beliefs (causal beliefs, illness coherence, personal control, and consequences) and number of coping strategies in relation to psychological adjustment (anxiety, depression and quality of life).

When addressing the primary research question "Are illness beliefs and number of coping strategies associated with psychological adjustment in caregivers of people with PD?" preliminary correlational analysis will be used to identify any significant associations between variables. Multiple-regression analysis will be undertaken to explore the association of illness beliefs (timeline and consequences) and number of

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### Secondary Research Questions

To address the secondary research questions, hierarchical regression will be used to address whether self-compassion is associated with psychological adjustment in people with PD and caregivers. Following identification of previously analysed predictor variables (i.e. number of coping strategies and illness beliefs) which account for variance in outcomes for participants with PD and caregivers, an additional block of analysis will be added to hierarchical multiple regression with the added predictor of self-compassion. This will allow for analysis of the role of self-compassion in psychological adjustment in participants with PD and caregivers at an individual level.

Should the above analysis find that there is a relationship between self-compassion and psychological adjustment in both people with PD and caregivers, then the dyadic relationship of self-compassion in psychological adjustment will be explored. Variance caused by previously analysed factors (e.g. illness beliefs and coping strategies) will be accounted for before conducting analysis with the use of the Actor-Partner Interdependence Model. This linear mixed model has been developed by Kenny et al. (2006) to allow for analysis of dyadic processes. This will be used to analyse the predictor of self-compassion separately on each dependent variable (anxiety, depression and quality of life).

## 8 REPORTING, PUBLICATIONS AND NOTIFICATION OF RESULTS

The results of the study will be written up for submission as a doctoral thesis as part of the Doctorate in Clinical Psychology and will be available through the University of Edinburgh library. The systematic review and the research article will be submitted to relevant peer reviewed journals focusing on psychological aspects of Parkinson's disease care such as 'Journal of Parkinson's disease'. It is hoped that Participants will be able to access a written summary submitted to Parkinson's UK research blog, which will be submitted to Parkinson's UK in July 2019. This will also be circulated to the participating NHS health boards.

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# Appendix 1.

Hoehn and Yahr (1967) Scale (Goetz et al., 2004)

## Stage One

- Unilateral involvement only usually with minimal or no functional disability

## Stage Two

- Bilateral or midline involvement without impairment of balance

## Stage Three

- Bilateral disease: mild to moderate disability with impaired postural reflexes; physically independent

## Stage Four

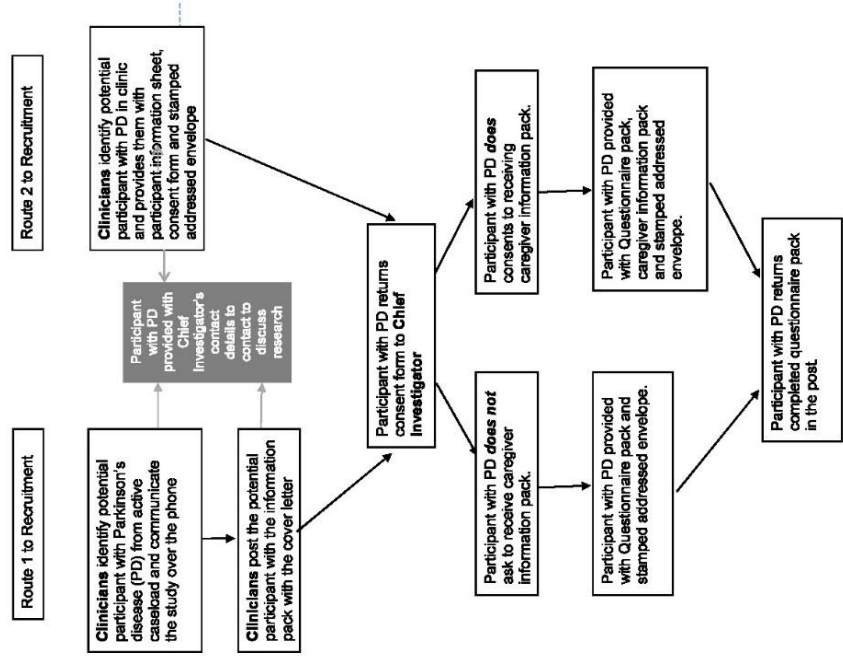
- Severely disabling disease; still able to walk or stand unassisted

## Stage Five

- Confinement to bed or wheelchair unless aided

# Appendix 2.

Protocol Flowchart for Participants with Parkinson's disease



## Appendix 8. Participant Information Sheet – Participant with PD

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*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs, and self-compassion.*

Lorna Hodge. Participant information sheet - participants with Parkinson's disease.  
Version 2. 26/04/18



THE UNIVERSITY  
of EDINBURGH



### Psychological adjustment in people affected by Parkinson's disease [Participant Information Sheet]

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to decide if you wish to take part. If you have any questions please contact the Chief Investigator (contact details at end of information sheet).

#### What is the purpose of the study?

This study aims to explore what factors contribute to better psychological adjustment in Parkinson's disease (PD) by conducting a survey with people with PD and their caregivers.

Psychological adjustment is a person's ability to cope with the needs of their situation, and the potential distress resulting from these needs. Therefore, this study hopes to explore how people with PD and caregivers cope with the changing demands faced as a result of PD, as well as how they cope with the potential distress faced as a result of these changing needs. This study will specifically explore whether people's coping strategies, beliefs about their illness, and self-compassion can help explain how they adjust to Parkinson's disease.

#### Why have I been invited?

We are seeking participants over the age of 18 years who have a diagnosis of idiopathic Parkinson's disease. Idiopathic Parkinson's disease means that the cause of the PD is not yet known.

#### Do I have to take part?

No, participation is entirely voluntary. If you do decide to take part you are still free to withdraw at any time and without giving a reason. Should you choose to withdraw after posting the consent form and questionnaires, you can contact the Chief Investigator by April 30th 2019 to ask for your data to be removed from the study. The contact details for the Chief Investigator can be found at the end of this document. Deciding not to take part or withdrawing from the study will not affect your current healthcare and future treatment.

#### What will happen if I take part?

You will receive six paper questionnaires in the post, after you have returned a completed consent form in the stamped addressed envelope provided. You will be asked to complete the six paper questionnaires. The total time taken to complete all the questionnaires will be approximately 60

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*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs, and self-compassion.*

Lorna Hodge. Participant information sheet - participants with Parkinson's disease.  
Version 2. 26/04/18

minutes. The questionnaires will be provided for you to complete at home. You can decide when you complete the questionnaires, and you do not need to be complete all questionnaires within the one day. We would ask you to return the questionnaires within the stamped addressed envelope provided.

We are also seeking caregivers of people with Parkinson's disease to take part in the study. For the purpose of this study, the following criteria outline the study's definition of a caregiver;

- Your caregiver normally lives with you
- Your caregiver is over the age of 18 years
- Your caregiver is directly responsible for some aspect of your care (for example they may provide physical and/or emotional support)
- Your caregiver is not a paid professional hired to care for your needs (although they may receive a carer's allowance)

Should you identify yourself as having a caregiver who meets these criteria, and you consent to them taking part in the study, you can indicate this on the consent form and this will involve you being sent a study information pack for you to give to your caregiver. We recommend discussing the study with your caregiver in advance to consenting to receiving a caregiver information pack.

*Please note that regardless of whether you identify a caregiver to participate in the study, all returned completed questionnaires will be included within the study, and will contribute towards the results.*

**What are the possible benefits of taking part?**

You may not gain a direct benefit from taking part in this study. The results from this study may inform on the future healthcare of people living with PD and their caregivers by identifying areas for healthcare professionals to focus on to improve the wellbeing of people with PD and caregivers.

**What are the possible disadvantages of taking part?**

The questionnaires have been used before in other research and are unlikely to cause distress, though of course, there is always the possibility that answering questions about what are personal and sensitive matters might be difficult for some. Therefore, if you find that the issues raised in the questionnaires are particularly distressing, you may wish to contact your General Practitioner, the health professional who informed you of the study, or the charities listed below.

Samaritans (tel: 116 123 ; web: <http://www.samaritans.org/>)  
Breathing Space (tel: 0800 83 85 87; web: <http://breathingspace.scot/>)

**Will my taking part in this study be kept confidential?**

The information gathered from the questionnaires will be kept confidential, and will not be shared with health professionals. The health professional who informed you of the study, and any of your other health care providers (e.g. G.P.) will not be contacted regarding your participation in the study. The information gathered from the questionnaires will also be kept confidential from caregivers.

*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs, and self-compassion.*

Lorna Hodge. Participant information sheet - participants with Parkinson's disease.  
Version 2. 26/04/18

**What will happen to the results of the research study?**

The study will be written up as a doctoral thesis and may be published as a peer reviewed journal article, with a summary of the research provided to Parkinson's UK for publication on their online research blog. You and other people would not be identifiable as a participant on any such scientific and academic publication, public or academic presentation.

**Who is organising the research?**

The study is being carried out as part of a Clinical Psychology Doctorate Thesis at the University of Edinburgh and NHS Lothian.

**Who has reviewed the study?**

The study proposal has been reviewed by the NHS Research Ethics Committee and University of Edinburgh Department of Clinical and Health Psychology Ethics Research Panel. A favourable ethical opinion has been obtained from both. NHS Management approval has also been obtained.

**You are welcome to contact us to ask questions about the research.**

**Contact Information for Chief Investigator:**

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Tel No: 0131 537 6901

This study is supervised by Dr Azucena Guzmán, Lecturer in Health and Ageing and Dr Liz Baikie, Consultant Psychologist.

If you would like to discuss this study with someone independent of the study team please contact: Dr Angus Macbeth on (0)131 650 3893 or email: [angus.macbeth@ed.ac.uk](mailto:angus.macbeth@ed.ac.uk)

If you would like to make a complaint please contact NHS Lothian Patient Experience Team, 2nd Floor, Waverley Gate, 2 - 4 Waterloo Place Edinburgh, EH1 3EG; Tel: 0131 536 3370; [feedback@nhslothian.scot.nhs.uk](mailto:feedback@nhslothian.scot.nhs.uk).

**Thank you for taking the time to read this information sheet.**



*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs, and self-compassion.*

Lorna Hodge. Participant Information Sheet for Caregivers.  
Version 2. Date 26/04/18



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**Psychological adjustment in people affected by Parkinson's disease  
[Participant Information Sheet for Caregiver]**

You are being invited to take part in a research study. Before you decide whether or not to take part, it is important for you to understand why the research is being done and what it will involve. Please take time to read the following information carefully and to decide if you wish to take part. If you have any questions please contact the Chief Investigator (contact details at end of information sheet).

**What is the purpose of the study?**

This study aims to explore what factors contribute to better psychological adjustment in Parkinson's disease (PD) by conducting a survey with people with PD and their caregivers.

Psychological adjustment is a person's ability to cope with the needs of their situation, and the potential distress resulting from these needs. Therefore, this study hopes to explore how people with PD and caregivers cope with the changing demands faced as a result of PD, as well as how they cope with the potential distress faced as a result of these changing needs. This study will specifically explore whether people's coping strategies, beliefs about the illness, and self-compassion can help explain how they adjust to Parkinson's disease.

**Why have I been invited?**

You have been identified as a caregiver of a person with idiopathic PD, and they have consented to you being approached to taking part in the study. Idiopathic Parkinson's disease means that the cause of the PD is not yet known.

**Do I have to take part?**

No, participation is entirely voluntary. If you do decide to take part you are still free to withdraw at any time and without giving a reason. Should you choose to withdraw after posting the consent form and questionnaires, you can contact the Chief Investigator by April 30<sup>th</sup> 2019 to ask for your data to be removed from the study. The contact details for the Chief Investigator can be found at the end of this document. Deciding not to take part or withdrawing from the study will not affect your current healthcare and future treatment.

**What will happen if I take part?**

You will receive five paper questionnaires in the post, after you have returned a completed consent form in the stamped addressed envelope provided. The total time taken to complete all

*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs, and self-compassion.*

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the questionnaires will be approximately 60 minutes. The questionnaires will be provided for you to complete at home. You can decide when you complete the questionnaires, and you do not need to be complete all questionnaires within the one day. Once all the questionnaires have been completed we ask that you return them in the enclosed stamp addressed envelope.

**What are the possible benefits of taking part?**

You may not gain a direct benefit from taking part in this study. The results from this study may inform on the future healthcare of people living with PD and their caregivers by identifying areas for healthcare professionals to focus on to improve the wellbeing of people with PD and caregivers.

**What are the possible disadvantages of taking part?**

The questionnaires have been used before in other research and are unlikely to cause distress, though of course, there is always the possibility that answering questions about what are personal and sensitive matters might be difficult for some. Therefore, if you find that the issues raised in the questionnaires are particularly distressing, you may wish to contact your General Practitioner, or the charities listed below.

Samaritans (tel: 116 123 ; web: <http://www.samaritans.org/>)  
Breathing Space (tel: 0800 83 85 87; web: <http://breathingspace.scot/>)

**Will my taking part in this study be kept confidential?**

Your questionnaire pack has a unique code to link your data to the person with PD who has consented to you taking part in the study. However, your information will be kept confidential. You will not be re-contacted after completing the questionnaire pack.

**What will happen to the results of the research study?**

The study will be written up as a doctoral thesis and may be published as a peer reviewed journal article, with a summary of the research provided to Parkinson's UK for publication on their online research blog. You and other people would not be identifiable as a participant on any such scientific and academic publication, public or academic presentation.

**Who is organising the research?**

The study is being carried out as part of a Clinical Psychology Doctorate Thesis at the University of Edinburgh and NHS Lothian.

**Who has reviewed the study?**

The study proposal has been reviewed by the NHS Research Ethics Committee and University of Edinburgh Department of Clinical and Health Psychology Ethics Research Panel. A favourable ethical opinion has been obtained from both. NHS Management approval has also been obtained.

**You are welcome to contact us to ask questions about the research.**

Contact Information for Chief Investigator:  
Lorna Hodge  
Trainee Clinical Psychologist

*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs, and self-compassion.*

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Psychology Department  
2nd Floor MacKinnon House  
Royal Edinburgh Hospital  
Edinburgh  
EH10 5HF  
Tel No: 0131 537 6901

This study is supervised by Dr Azucena Guzmán, Lecturer in Health and Ageing and Dr Liz Baikie, Consultant Psychologist.

If you would like to discuss this study with someone independent of the study team please contact: Dr Angus Macbeth on (0)131 650 3893 or email: [angus.macbeth@ed.ac.uk](mailto:angus.macbeth@ed.ac.uk)

If you would like to make a complaint please contact NHS Lothian Patient Experience Team, 2nd Floor, Waverley Gate, 2 - 4 Waterloo Place Edinburgh, EH1 3EG; Tel: 0131 536 3370; [feedback@nhslothian.scot.nhs.uk](mailto:feedback@nhslothian.scot.nhs.uk).

**Thank you for taking the time to read this information sheet.**

## Appendix 10. Consent Form – Participant with PD

Page 1 of 2

*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion.*

Lorna Hodge. Consent Form for participants with Parkinson's disease. Version 2. 26/04/18



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### Consent Form

**Study Title:** Psychological adjustment in people affected by Parkinson's disease

**Participant ID:** \_\_\_\_\_ (official use only)

**Chief Investigator:** Lorna Hodge

**Supervisors:** Dr Azucena Guzman and Dr Liz Baikie

Please initial  
in the boxes

1. I confirm that I have read and understood the information sheet, dated 26/04/18, Version 2 for the study. I have had the opportunity to consider the information and ask questions. I understand that my participation is entirely voluntary.
2. I understand that I will be requested to fill in questionnaires which will be posted to me once this consent form has been received by the Chief Investigator. Please provide your address on the other side of this page.
3. I understand that relevant sections of my data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsors (NHS Lothian and the University of Edinburgh) or from the/other NHS Board(s) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records.
4. I understand that data will go on to a written report and might be published in scientific journals which may be disseminated to the wider research community with my details anonymised.
5. I also consent to my caregiver taking part in the study, resulting in receiving a caregiver information pack being posted to my address for me to give to my caregiver.
6. I agree to take part in the above study.

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion.*

Lorna Hodge. Consent Form for participants with Parkinson's disease. Version 2. 26/04/18

If you consent to participate in the study then please provide your details below for you to receive the questionnaire pack;

**Address of Participant;**

House Name/Number: \_\_\_\_\_

Street: \_\_\_\_\_

Town: \_\_\_\_\_

Postcode: \_\_\_\_\_

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

## Appendix 11. Consent Form – Caregiver

Page 1 of 2

*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion.*

Lorna Hodge. Consent Form for caregivers. Version 2. 26/04/18



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### Consent Form

**Study Title:** Psychological adjustment in people affected by Parkinson's disease

**Participant ID:** \_\_\_\_\_ (official use only)

**Chief Investigator:** Lorna Hodge

**Supervisors:** Dr Azucena Guzman and Dr Liz Baikie

Please initial  
in the boxes

1. I confirm that I have read and understood the information sheet, dated 26/04/18, Version 2 for the study. I have had the opportunity to consider the information and ask questions. I understand that my participation is entirely voluntary.
2. I understand that I will be requested to fill in questionnaires which will be posted to me once this consent form has been received by the Chief Investigator. Please provide your address on the other side of this page.
3. I understand that relevant sections of my data collected during the study may be looked at by individuals from the regulatory authorities and from the Sponsors (NHS Lothian and the University of Edinburgh) or from the/other NHS Board(s) where it is relevant to my taking part in this research. I give permission for those individuals to have access to my records.
4. I understand that data will go on to a written report and might be published in scientific journals which may be disseminated to the wider research community with my details anonymised.
5. I agree to take part in the above study.

☐☐☐☐☐

\_\_\_\_\_  
Name of Participant

\_\_\_\_\_  
Signature

\_\_\_\_\_  
Date

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

*Psychological adjustment in people with Parkinson's disease and caregivers: the role of coping, illness beliefs and self-compassion.*

Lorna Hodge. Consent Form for caregivers. Version 2. 26/04/18

If you consent to participate in the study then please provide your details below for you to receive the questionnaire pack;

**Address of Participant;**

House Name/Number: \_\_\_\_\_

Street: \_\_\_\_\_

Town: \_\_\_\_\_

Postcode: \_\_\_\_\_

Original (x1) to be retained in site file. Copy (x1) to be retained by the participant.

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